A PARTICIPATORY RESEARCH PROJECT:

Exploring the views and experiences of Black and South Asian communities in the UK on patient data and its uses

Diverse voices on data

CLEARVIEW RESEARCH

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About Us

ClearView Research (ClearView/CVR) is an audience insight and strategy agency. We are specialists in working on research, evaluation and engagement projects with young people, minority ethnic groups, culturally diverse communities, people with protected characteristics and those who often go unheard. We are committed to ensuring that our work is always inclusive and equitable. We strive to ensure that all our participants enjoy the research process and find it accessible, engaging and empowering. We ensure that their voices are central in the materials (e.g. reports and frameworks) that we produce. **We work best with organisations who give a damn and want to make a genuine impact.**

We are proud to be:

- **An MRS company partner** that upholds and acts in a manner compliant with the strict ethical and rigorous rules contained in the MRS Code of Conduct.
- **A Certified B Corporation,** which is a certification only awarded to organisations that exemplify the highest standards of social corporate responsibility, transparency and accountability. Our Impact Business Model is recognised for its intended design to create positive outcomes for all our stakeholders and address community-oriented challenges. Our standards and values serve as a foundation for social, economic, environmental and governance best practices for businesses. We exist not just for profit but to benefit all people, communities, and the planet.

Find out more at **www.clearviewresearch.co.uk**

Understanding Patient Data aims to make the use of patient data more visible, understandable and trustworthy for patients, the public and health professionals. Based at the Wellcome Trust, the programme seeks to bring transparency, accountability and public involvement to the way patient data is used.

Find out more about our work at **www.understandingpatientdata.org.uk**

Executive Summary

The Covid pandemic has seen poorer health outcomes for Black and South Asian people, drawing attention to existing health inequalities. It has also exposed the frequent gaps in patient health records on ethnicity and on clinical information and social determinants of health, such as blood pressure and smoking status.[1, 2, 3] As a result, policy focus on collecting more patient ethnicity data to deliver more equitable outcomes and vaccination coverage during the pandemic has increased. However, Understanding Patient Data felt that to create lasting change, it is important first to understand the reasons behind data inaccuracy and incompleteness.

We, in partnership with Understanding Patient Data, undertook a qualitative research study to examine the views and experiences of people from Black and South Asian communities in the UK on how their patient health data is collected and used and their aspirations for how this should be done in the future. We took two parallel approaches to collecting insights from people in these Black and South Asian communities: community research and exploration labs. Community research is a peer-led co-creation approach to research, where members of the community of interest are trained and supported to conduct discussions with other members of their community. Exploration labs are similar to focus groups. They allow participants to share their experiences, views and ideas and incorporate engaging visual and graphic methods where participants can draw out and map counter-responses. We engaged a total of 321 people from Black and South Asian communities across the two parallel workstreams.

Overall, most of the participants came into the research feeling that they had a good understanding of what patient data is, how and where it is collected, and its uses. However, when they were provided with more information it came to light that many of them were not aware of how their data could be used beyond their individual care.

As well as uncertainty about how their data is used, some participants expressed nervousness about sharing their data. The reasons behind this included fears that the NHS would share their data with third-party organisations they would prefer not to share their data with (such as insurance companies) and fears that the NHS would not be able to protect their data from being stolen by external companies due to data breaches. Despite these fears, most of the participants reported that they regularly and willingly provide their data, and they are hopeful that their data is being, and will be, used to improve services and treatments for themselves and their communities. However, they explained that they have yet to see this happen, and this lack of evidence of real change and the practical benefit of sharing their information left them feeling reluctant to share it.

Many participants also described how they do not see evidence of data on their race, ethnicity, culture, or religion being considered by local services. They described situations of racial and ethnic discrimination where they were unable to receive a diagnosis or appropriate treatment because their ethnicity or the colour of their skin were not considered.

The reasons they suggested for this included the healthcare professionals' lack of time or their training and education being focused on White people, meaning they are less aware of conditions more prominent in other ethnic groups or symptoms more relevant to people from ethnic minority communities. Reasons for this could include biased education and resources, with examples reflected in several research studies.[4, 5, 6] The significance of this was emphasised in a campaign launched by the NHS in January 2020 on the need for more culturally and racially sensitive approaches to care.[7]

Public Health England has also highlighted how gaps in the quality of the recording of data about ethnicity, faith, and other characteristics such as occupation impact health inequalities.[8] We explored this topic further with participants to understand if they faced any barriers or challenges to providing this data when accessing healthcare. We found that although most participants are willing to provide their data, they are not always able to provide the level of detail that they would like. Many of the forms that participants described using, both paper and online, offer only limited options to respond to questions about their identity, including questions on race, ethnicity, culture, and religion. This means that for some participants it is difficult to respond honestly to the question as none of the options describes their ethnicity accurately. Some of the participants described their frustrations when faced with the challenge of selecting their ethnicity and described how not having an option that they felt appropriately described them left them feeling excluded or unseen. This raises two challenges for the collection of data on race or ethnicity. First, more categories should be offered to allow people to identify a category that best defines their identity. Secondly, people should have the option to provide multiple categories of information as identity can incorporate an intersectional mix of attributes related to colour, nationality and ethnic or national origins.[9]

While exploring participants' experiences of providing their data when accessing healthcare, we also discovered that the forms used to collect this data can also be confusing to people who do not speak English or who did not grow up in the UK. Participants explained that often they will not have seen these types of questions or categories previously, as in their countries of origin data is collected differently. For example, they are not asked to categorise their race or ethnicity as they are in the UK, and language or abbreviations such as DOB for date of birth are unfamiliar to them.

One way to avoid the limited nature of forms for providing detail about complex topics such as identity would be to provide the information verbally, through a conversation with a healthcare professional. However, none of the participants could recollect having a conversation of this type, and one participant, who works within the NHS, even reported that they had witnessed colleagues taking shortcuts when recording this type of information, preferring the use of collective or overarching categories over recording more detailed and specific data. The key point to note here is how important this detailed information is, both for an individual's healthcare and to inform and improve communication, treatment, and services for minority communities. If we want to be able to provide patient-centred, high-quality care it is vital to understand the individual patient, including their diet, herbal remedies they may use, their cultural or religious beliefs and attitudes, and any associated impacts these may have on their health or care. Without this information there is an increased chance of mis- or under-diagnosis, providing incorrect treatment, and poorer health outcomes. At a community level, if we do not record, analyse and report detailed information about attitudes, knowledge and practices that may impact health and health outcomes, broken down into as much detail as possible, then we lose out on learnings that can be applied to larger community groups and potentially save lives.

Despite the challenging experiences they have faced, most of the participants in the research study were optimistic about what could be done to improve how their data is collected and used in the future. They spoke about how improving the cultural and medical knowledge of healthcare professionals and encouraging more diversity in both healthcare and data analysis could lead to great improvements in both treatments and services for people from Black and South Asian communities across the UK. However, they also pointed out that to achieve real change, trust between these communities and the system and the individuals within it will need to be improved. They were mostly hopeful that this trust could be achieved, but this will require a commitment to anti-racist and anti-prejudiced practice and clear feedback loops that communicate back to communities the research findings and the actions that are being taken to create positive change.

To create a future where people from Black and South Asian communities are better informed, better engaged and have a say in the design of processes that collect and use their health data, we have provided some recommendations for Understanding Patient Data, healthcare professionals and the wider health sector to move forward:

1. **Healthcare professionals need the resources and training to be equipped to have conversations with Black and South Asian people about what patient health data is and how it is used.**
2. **Research is needed to find a new method to collect identity information, including race and ethnicity, which is more inclusive, so that patients can more easily and accurately provide this information.**
3. **People from Black and South Asian communities should be involved in decisions about the prioritisation of research and improvement involving their data.**
4. **To improve health outcomes, health data should be used to ensure better and more appropriate representation in datasets and for research into conditions that disproportionately affect people from Black and South Asian backgrounds.**
5. **The NHS must commit to eradicating racial and ethnic discrimination, which affects the way patient data is collected and used.**

Project Background

The Understanding Patient Data (UPD) team commissioned ClearView to conduct a study to achieve the following objectives:

- To explore Black and South Asian peoples' thoughts on health data collection and use, why health records are often incomplete or incorrect, and what aspects of data collection and use matter to them.
- To understand what it means to be represented: peoples' perceptions of benefits or risks when it comes to being included or not included in health data collection.
- To gain insight into the particular questions, concerns, sensitivities and aspirations that people from Black and South Asian backgrounds have concerning the collection and use of data in their health records.

Methodology and Approach

Approach

Our approach was designed to gain deep insights into Black and South Asian people's thoughts on patient data collection and use. This included collecting insights into why health records are often incomplete or incorrect, what it means to be represented in data, and the concerns, sensitivities, and aspirations for the future that people from these communities have for the collection and use of the data in their health records.

ClearView sought to engage a range of people from Black and South Asian communities across the UK to discuss their thoughts and experiences concerning patient data. This was done through exploration labs facilitated by ClearView and by community research, both of which are methods developed by ClearView as participatory ways of engaging people in research. Like focus groups, exploration labs are discussion groups where participants are encouraged to explore their thoughts and ideas through group discussion. While some structured questions were asked as part of this project, space was given for dynamic interaction and group discussions, and people often took the lead in progressing the discussions. Community research involves upskilling a group of community or peer researchers in research methods, design, research bias, community engagement and data analysis and actively partnering with them to design, conduct, analyse, report, and disseminate the research as equal partners within the research team. Both community researchers and exploration lab participants were paid for their time and contributions.

UPD were keen on ClearView having representation from across the UK as far as possible in the exploration labs. Based on the geographical representation of Black and South Asian communities across the UK, as per the latest Office for National Statistics (ONS) data (2011), we sought to engage people from the following regions of the UK:

- **London and South East England**
- **West and East Midlands**
- **Yorkshire and Humber**
- **Wales**
- **Scotland**

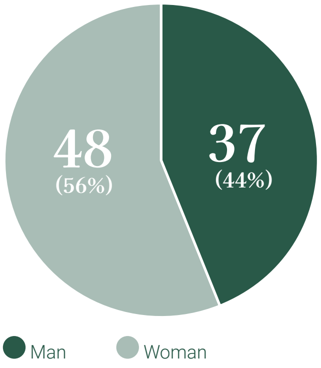
We know from previous recruitment that engagement with people from Black and South Asian communities living in London and South East England would be higher than with people from these communities living in other areas of the UK. Therefore, we focused our recruitment on other geographical areas to ensure a broader geographical representation within the sample and were able to engage participants from all the selected regions. All sessions were facilitated by two members of our team and were held on Zoom, and participants were able to register for the session time that suited them.

Participant Profiles

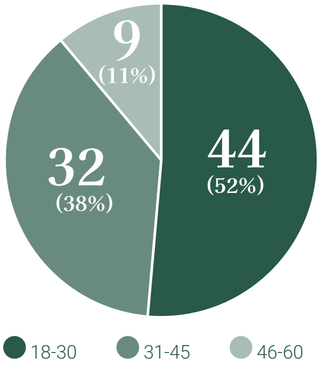
A total of 321 people participated in this research, including the eight community researchers. Of these, 85 participated in the ClearView-led exploration labs, while 228 participated in the peer-led community research. Further details of the demographic profiles for both the exploration labs and community research are included below.

Exploration labs

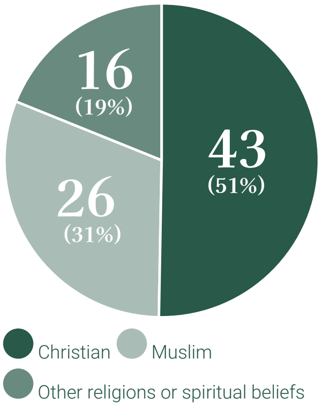
Gender



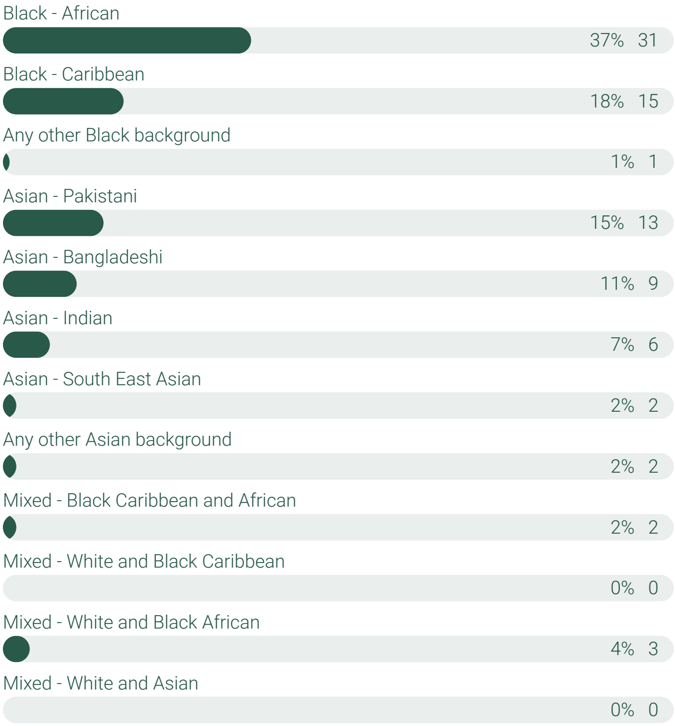
Age



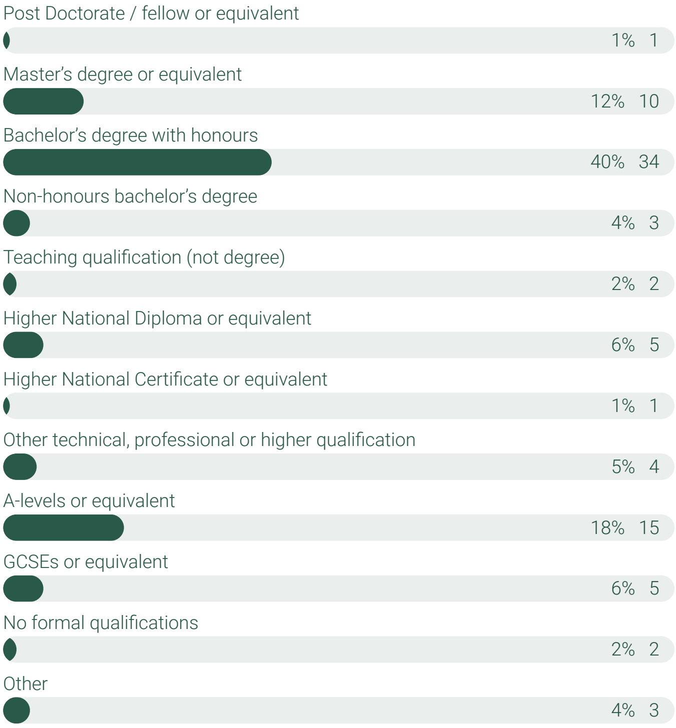
Religion



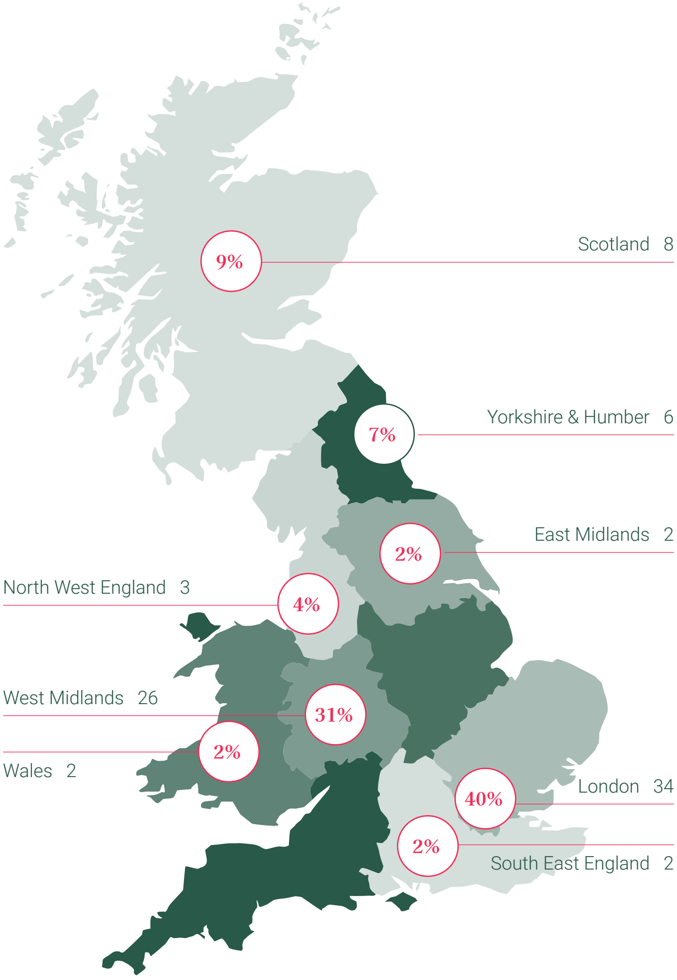
Ethnicity



Education level



Geographic Location

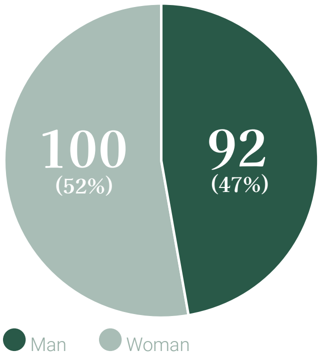


Ethnicity

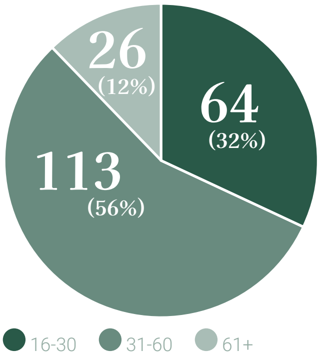
Ethnicity	%	Total
African	1%	2
Arab	1%	1
Asian	5%	10
Asian - Pakistani	1%	1
Asian/African	1%	1
Bangladeshi	14%	26
Bengali	2%	3
Black African	19%	35
Black African/Caribbean	1%	1
Black British	1%	2
Black British African	1%	1
Black Caribbean	2%	3
British Bangladeshi	1%	1
British Pakistani	1%	2
Ghanaian	6%	11
Indian	15%	28
Iranian	1%	1
Mauritius	1%	1
Nigerian	2%	4
Pakistani	24%	44
South African	1%	2
Trinidad	1%	1

Community research

Gender*



Age*



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* The percentages for ethnicity, age and gender for the community research participants are based on the total number of participants who felt comfortable sharing this information with the community researchers.

Exploration labs

We conducted a total of 11 exploration labs engaging 85 participants over three months from October to December 2021. Exploration labs are like focus groups. They allow participants to share their experiences, views and ideas and incorporate engaging visual and graphic methods where participants can draw and map counter-responses. From our experience and evidence from the literature (Bagnioli, 2009), participatory methods work well, as they break down barriers to engagement in the research process.[10] They are particularly effective with young people, seldom-heard groups, those for whom English is an additional language, and those who may have special educational needs and/or come from neurodiverse backgrounds.

Exploration labs for this project lasted approximately 70 minutes and were led by one of the ClearView Team, while another member of the ClearView team took notes. Participants were made aware of the nature of the project before joining but were also told again at the beginning of the exploration labs, including an overview of UPD and what the purpose of the project was. Structured and unstructured questions were then asked (see Appendix A), and participants were also told that they could contact a member of the ClearView team if they had specific questions about the management of their information.

All exploration labs began with a set of questions to get a better understanding of the participants' existing knowledge of patient data. Then they were shown an infographic providing a detailed explanation of how patient data is collected and used, as seen in Figure 1. This allowed us to establish the group's existing level of understanding before confirming the details of what currently happens, to avoid any confusion for the rest of the discussion about what is meant by patient data and how it is collected and used.

Each exploration lab was live illustrated while it was happening. Live illustrations are drawings that capture what is being discussed during the exploration lab. Near the end of the discussion, we presented the live illustration to the participants so that they could constructively assess it to make sure it was reflective of what had been discussed and did not misrepresent the views and experiences they had shared during the discussion. These illustrations were then used to guide analysis and discussions around the main themes and insights from the research. All these illustrations are included in the appendices.

Community research

In addition to the exploration labs, we facilitated peer-led community research. Where the exploration labs achieved a depth of engagement and insight, the community research insights brought a breadth of experience.

We trained eight community researchers from Black and South Asian communities in our Peer Research Education Programme. The programme focuses on research and engagement in the community and includes modules on research design, research methods, fieldwork approaches, community engagement, analysis, and reporting. Following the training, we worked closely to assist the community researchers in designing their research questions and methods, recruiting participants, and engaging with their local communities. Each community researcher spoke with a minimum of 20 people in their community.

To ensure comparable outputs, the community researchers co-designed several questions to understand people's understanding of patient data collection and use and their related experiences. Based on the participants that each community researcher chose - for example, work colleagues, friends, family members, congregations, and other members of their community – they then followed up with further questions to gather more in-depth insights. The community researchers also used the infographic in Figure 1 to share with research participants what is meant by patient data and how it is collected and used.

The community research fieldwork was carried out over three months from November 2021 to January 2022, with regular check-ins taking place with the ClearView team and the community researchers, to ensure they felt supported throughout the process. This approach gave control of the community research element back to people in the communities, to decide what the focus of the conversations should be and create the opportunity to engage and gather insights from communities who normally may not participate in research or share their opinions. Some demographic characteristics were collected as part of the community research fieldwork, namely ethnicity, age, and gender, but participants did not have to provide these details to participate. We made the question on ethnicity open-ended so that participants could describe their identity in their own way. These approaches to the collection of demographic details were put in place to ensure that this was not a barrier to participation.

We also worked closely with the community researchers to inform the discussions in the exploration labs and worked with the group to sense-check the research findings at the end of the process. This enabled us to contextualise the findings properly, represent them correctly and frame them sensitively and appropriately.

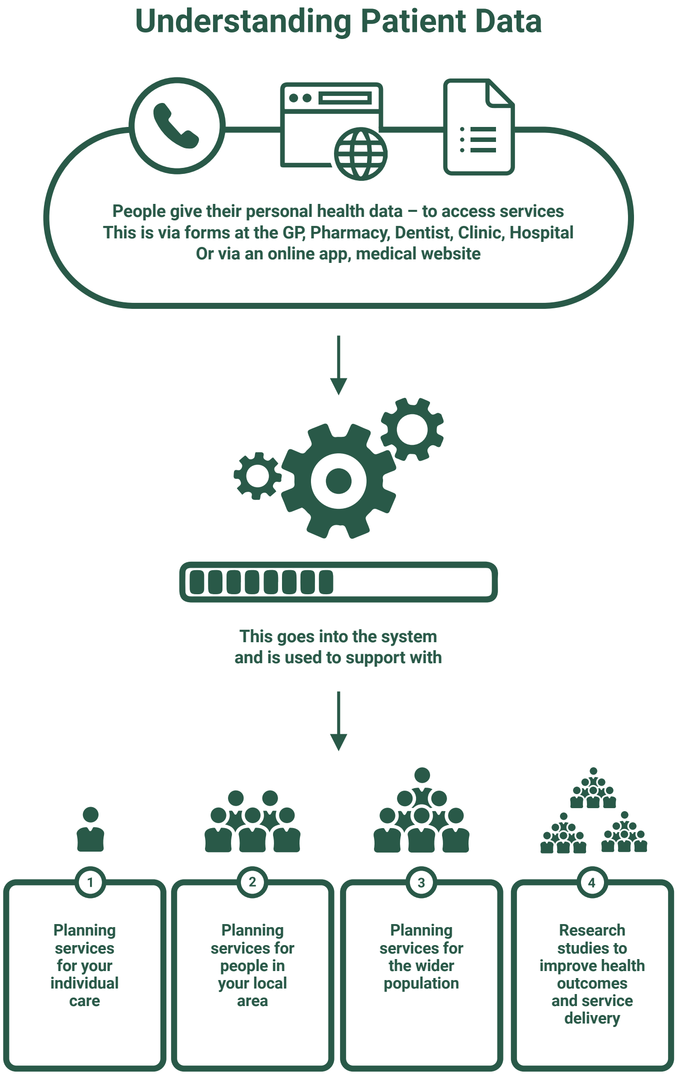
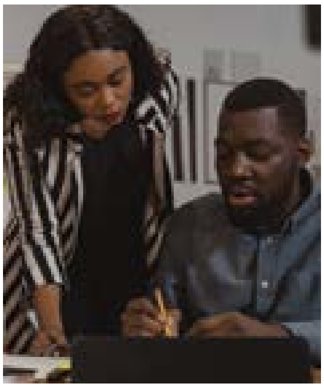


Figure 1: Infographic for Exploration Labs and Community Research



Recruitment strategy

We used a combination of convenience and quota sampling to recruit participants for this study. In convenience sampling, participants are selected based on their availability and willingness to participate. Quota sampling then involves recruiting people from specific groups with predetermined characteristics, in this case, gender, age, and ethnicity. This method comes with the risk of missing the views or experiences of certain groups of people who do not tend to volunteer to participate in research. However, we counteracted this by using a number of our sampling approaches and techniques as detailed below.

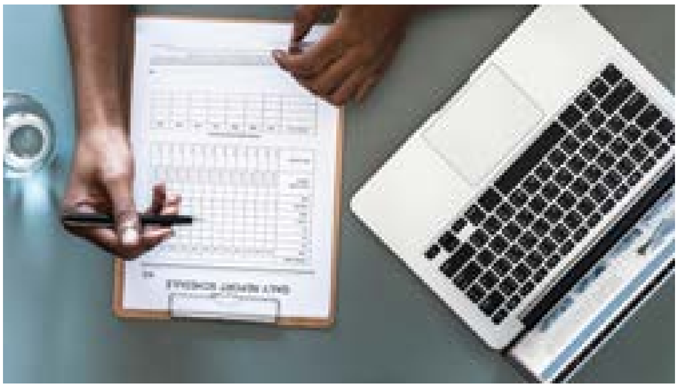
This tried and tested approach results in high-quality participation, interest, and commitment to our research projects. It has also helped us to build relationships of trust with a large number of communities, organisations, and individuals across the UK.

Recruitment approach

Often, we are asked to do research involving populations that are considered 'difficult to reach', either because they do not normally engage in research, are not proactively engaged in research, or are part of a small population. For this specific research project, we used the following techniques to assist with recruitment.

Community engagement and networks – To achieve our representative sample size, our recruitment strategy included using our personal networks and our CVR Community, which has approximately 2000 people from Black and South Asian communities across the UK. This helped us to recruit eight paid community researchers from the Black and South Asian communities to work alongside us to help us engage people to participate in both the exploration labs and community research.

Leader-led – We approached community leaders, such as leaders of churches, sporting groups, youth organisations, community organisations and schools, to help us to recruit for this research project. Having our research opportunities shared by community leaders significantly helped us to recruit people who would normally not engage with research, ensuring their voices were included.



Snowballing – By building relationships of trust with those who participate in our research we can rely on them to share this opportunity and to encourage their peers, families, and communities to participate.

Recruiting from underrepresented communities
We have found through conducting our own research that there are many different reasons why people from underrepresented communities do not participate in research, these include a lack of trust, being time-poor, and not being made aware of the research opportunity. Our recruitment approach addresses these barriers and helps ensure that we can effectively recruit participants from communities that are often underrepresented in research. This approach involved:

Trust – We work hard to engage with and listen to the communities we work with to ensure that when we conduct research we are representing them fairly and justly. This commitment to being a voice and advocate for these communities means that ClearView Research is a trusted organisation that people feel comfortable engaging with. With this research topic being controversial and difficult for some, we had to ensure that trust and transparency were front and centre for this research and that we provided participants with information upfront about the research aims and objectives and who was funding the project, as well as providing them with the opportunity to ask questions throughout the process.

Clear and open communication – We use clear language that can be easily understood so that people who participate in research with us know exactly what they are agreeing to, how their information will be used, and how it will be protected. We make ourselves available for questions and are always willing to offer explanations or to talk about any participant concerns.

Appropriate incentives – We value all contributions that participants give when working with us. To make sure participants' time was valued in this project, we offered incentives to participants who took part in the exploration labs and those recruited as community researchers. We also promised to update those who participated in our research with the findings and outcomes of the research so that they can see the value of their participation.

Meeting them where they are – Often people from underrepresented communities access and engage with information in different ways. We chose to meet the people we wish to engage where they are, using our networks and creating new ones to reach the population we wanted to work with.

Study Limitations

It is important to note that though the insights in this report reflect the lived experience and reality of the people who took part in the research, our findings cannot be generalised to represent the wider population of all people from Black and South Asian communities. This is a qualitative piece of research that should be used to gain a broader understanding of the views and experiences of people from Black and South Asian communities to complement broader quantitative research and future service delivery.

Scope - This piece of research was focused on gathering insights from Black and South Asian communities about their existing understanding of how their patient data is collected and used, their views and experiences of how their data is collected and used, and their aspirations for how this could be improved in the future. Due to the participatory nature of this research, participants' discussions touched on several other relevant topics, including engagement with healthcare systems and how they would like to define their identity characteristics, such as ethnicity or religion, better. However, as these insights were not the focus of this piece of research they were not explored in detail, so we are unable to provide a thorough analysis of these topics here. At best we can recommend areas that should be explored further in future research.

Sampling approach - The sampling approach we used to identify exploration lab participants, community researchers, and community research participants was driven by convenience sampling. This is where participants are selected based on key characteristics, their availability and willingness to participate. The main disadvantage of this approach is that there are often already underlying differences between those who volunteer to participate in research and those who do not, which could lead to the views or experiences of certain groups not being represented in the research. The links that the community researchers have to their communities will have helped to overcome some of these limitations, as they can encourage a broader reach and engagement with the research. However, there will always be a risk that certain groups are underrepresented when using this sampling method.

To overcome this sampling bias further, we adapted the convenience sampling method to include a quota-driven sampling approach, where participants from specific groups with certain characteristics were included. In our final sample, we ensured representation across demographics, including people from a spread of geographic regions from both Black and South Asian communities.

Population representation - The final sample included a broad representation of a mix of demographic characteristics of Black and South Asian communities. This final sample does not proportionally reflect the number of people from these ethnic groups in the UK population as a whole, nor does it reflect the numbers of people within these communities who have specific religious beliefs, are of specific ages, are first- or second-generation migrants or have attained specific education levels. In quantitative research, where the intention is to draw conclusions that can be extended to represent the views of a wider population group, it is important to ensure that certain characteristics of that population group are proportionally met within the sample. However, in qualitative research, where the focus is on gaining a deeper understanding of a situation rather than determining the number of people affected, it is more important to include a broad range of views and experiences so that important insights are not missed. This means that, while the sample included in this research may represent one demographic group more than another, it is a good sample for the aims of this research.

Comparisons between demographic groups – We examined the final transcripts from the exploration groups and the data collected by the community researchers to identify any important differences in how participants from different demographic groups, for example, age, gender, ethnicity, or religion, differed in their views and experiences of how patient data is collected and used. For the most part, we identified no substantial differences in the views or experiences of people from these different groups. Those differences that we did note are discussed in the relevant section of the findings. However, as it was not one of the objectives of this research, we acknowledge that there may be differences in the views and experiences of different demographic groups that are not picked up in this type of research design, qualitative group discussion. Further research using interview or quantitative techniques could prioritise examining differences in the views and experiences of different demographic groups.

Key Findings

1. Black and South Asian communities generally understand what is meant by patient health data (or information) but there are gaps in knowledge about the collection and uses of patient data.

Most participants from both the exploration labs and community research had a good understanding of what patient data is and how it is collected. At the start of the exploration labs, participants were asked whether they understood what is meant by patient data, to which a large proportion explicitly said "yes". Comments included the following:

> "(It is) confidential information about patients' records stored in databases."

(Mixed - White and Black African, Man, 25-30 years)

> "(It is) GP and hospital records that might be shared with relevant health organisations."

(Asian - Bangladeshi, Woman, 21-24 years)

> "Isn't it just the data, the information that you have on the patient?"

(Black - Caribbean, Man, 36-40 years)

> "Your life, when you might be eligible for certain health screenings."

(Asian - Pakistani, Man, 46-50 years)

> "Similarly, any records held, health records by your doctor or records held by the hospital where you've been for any kind of appointments, visits where there's been any kind of results or injuries or incidents that have happened throughout your life."

(Asian - Pakistani, Man, 51-55 years)

However, in both the labs and the community research there were gaps in their understanding of how such data is used in the wider healthcare system. This would explain why those that do not share demographic data do not see the value of this information for improving healthcare and related services. Even after seeing the infographic (see Figure 1 on page 13 above), many participants from the exploration labs commented on not being aware of the link between providing data and its use in planning local and national services.

"I never think of the wider impact that the information collected from me could have on society or in planning for the wider population. So, I think that will be in my mind moving forward, that providing this information or choosing not to, and how it will impact health care moving forward."

(Black Woman, 25-30 years)

"I never thought that they used the information to provide special services for the local area, so I think this is something new to me and I think it's quite interesting."

(Black African, Man, 31-35 years)

Therefore, while many of the respondents appeared to have a clear understanding of what patient data include, how they are collected and used, we can see that many participants were surprised at the range of ways their data is used.

Due to sample size and data collection techniques, the qualitative research was not able to determine which groups are more likely to have a greater or lesser understanding of the uses of patient health data. However, we did observe that those who are younger or have attained a higher level of education had more to say about how patient data is used. Further quantitative data could explore this insight further to determine if some characteristics determine the level of knowledge held about patient data collection and use.

2. Many people from Black and South Asian communities have low levels of trust in the NHS and are concerned about how their data will be protected.

Trust is a major factor in citizens' compliance with public health and public health measures, as highlighted by Dr Luisa Enria et al. (2021) in their PLOS One paper that showed how the willingness of people to follow the rules and engage can evaporate when trust is gone[11].

We were aware of the historical and societal issues relating to trust among Black and South Asian communities, so we considered the Trust Confidence and Cooperation Model (TCC) when designing our exploration labs. The TCC model was developed by Siegrist (2003) and differentiates "social trust" (based on similarity), "shared values" and "confidence" (based on past experiences)[12]. Similarly, we referred to Twyman's view on trust (2008) as 'trust in motives' and 'trust in competence', in our thinking and development of questions and discussion prompts[13]. We found that doing this enabled participants in the exploration labs to be more specific when referring to trust, which we understand varies depending on the context.

To start a discussion on trust in the exploration labs, we asked our participants the following question:

Do you trust the NHS and its related organisations with your health data?

a) NHS hospital trusts

b) Local NHS services (GP surgeries, dentists, clinics)

c) NHS institutes (research and training, i.e. NIHR)

d) Public Health England

e) Research institutes

f) Health-related charities

We saw a variety of responses to this question: Some people responded with an outright "no" to trusting the NHS more generally or services they had interacted with more specifically, though no one named specific services that they did not trust with their data. Interestingly, whereas some people responded with an outright 'no' to the above question, there were no outright 'yes' responses. Even when people were prompted to elaborate some chose not to, which indicates a consistent trend towards not trusting the various NHS services with their data. Where respondents did provide more detail, some said they trusted local NHS services and some health-related charities and organisations with their data, but not the NHS as a whole.

"I am wary because I don't think the data is used for the purpose it is supposed to be used for. I also feel like a lot of the information collected on medical forms are not used for research purposes to improve services for Black people and I also believe it is shared with third parties without my consent."

(Black African, Man, 31-35 years)

"If it can be shown that it won't be sold for use by big pharma, then I guess I wouldn't mind it being used for research. I don't know if that's even possible, so I am wary of any sharing."

(Asian - Pakistani, Woman, 21-25 years)

"I would say overall, as a rule, I do [trust the NHS], but just, I know it might be a slightly random point, but I remember when the whole track and tracing stuff was coming out there was a bit of a lack of transparency from the NHS in terms of where the data was going to. And I think of that kind of news story. It made me think actually that the NHS, you know, it and its related bodies have a lot of information on us. And actually, I don't know where any of that is. So, I would say probably not as trusting recently."

(Asian - Bangladeshi, Woman, 46-50 years - exploration labs)

Participants also referred to a lack of trust in the technical competence of the NHS services concerning the handling and storage of their data, especially the concern that they might share their data with private companies, even if unintentionally through data breaches. Some participants mentioned previous coverage of NHS data breaches in the news, including coverage from June 2021 revealing that there had been more than 3,557 personal data breaches across the health sector in the previous two-year period[14]. People spoke about not always knowing how the NHS shares and manages their data:

"Yeah, I would say before I would have been trusting because I would have assumed everything was going to what you've just told us now to try and improve services overall for individuals, for communities, whatever. But, yeah, I think since recent news headlines, it's made me think actually that I could have a bit of mistrust now with giving my data."

(Black African, Male, East Midlands, 25-30 years)

"The left hand doesn't know what the right hand is doing. I don't trust the processes."

(Black African, Male, West Midlands, 36-40 years).

Therefore, based on both the Siegrist (2003) and Twyman (2008) approaches to trust, participants did not appear to have confidence in the NHS, nor did they express 'trust in motives' or 'trust in competence'. We explore "social trust" (history of poorer health outcomes) and "shared values" (negative experiences of the system) in the following sections.

3. Black and South Asian communities believe that data can be used to improve health outcomes in their communities, but they do not see this happening in reality.

Building on the discussions around trust, we wanted to explore people's feelings about the usefulness of sharing demographic data and whether they felt sharing it would lead to better health outcomes for their respective communities.

As discussed above, in most cases participants said they do share their demographic details when asked for them. When participants in the exploration labs were asked how comfortable they feel responding to questions about their ethnicity, 33 said that they feel comfortable responding to demographic questions, 32 said they do not, and the rest responded that they were either indifferent or unsure. This spread of responses was fairly even across all demographic groups, although Black African participants were the most vocal about their willingness to provide their data (i.e. 10 of the 33 respondents who said they feel confident were Black African).

Similarly, the community researchers reported that most of the participants in their research were willing to share their patient data when asked for it, but that they found some questions difficult to answer and that participants had concerns about how the data would be used.

> **"I knew my information would help the health services that have been rendered to people like me, so I was comfortable as long as my name wasn't going to be online, but my responses would help another person, so I knew, and I was comfortable with that."**

(Black - African, Man, 31-35 years)

> **"I think the reason why we are asked is a good thing. Reason being that we are all different. We all know we are different, and we all come from different backgrounds. And being identified gives us our individuality. Also, if our information is going to be gathered for statistical reasons to find out, like the earlier gentleman said, that it might highlight that certain illnesses are higher in certain different communities then it is a good thing."**

(Asian - Bangladeshi, Woman, 46-50 years)

> **"I'm comfortable with sharing my data, I don't have a problem with that, but I don't know how much faith I have in the system or what is the outcome going to be from it and how much it's going to reach and make a difference to the people who are in most need."**

(Asian - Bangladeshi, Woman, 41-45 years)

When we showed participants the infographic that illustrated the relationship between sharing patient data and designing services at the start of the sessions, some were not necessarily aware of the link between their patient data and local services. We opened up the discussion to see if participants believed there is a specific link between their patient data and better health outcomes for Black and South Asian communities. We did this by asking participants the following:

Do you believe that providing your health data for research and/or service design will improve services for Black and South Asian communities? If yes, why? If no, why not?

Most participants who replied to this question explicitly said "yes". However, they made it clear that although, in theory, providing data could help improve services they did not feel this was happening. Some of the participants even went so far as to say they believed the healthcare needs of Black and South Asian communities were not a priority in research and service design.

Some of the comments from those who said "yes" were:

> "The academics, the scientists, will need to know a broad spectrum of people to be able to draw data from because, you know, a single case in isolation doesn't give you a thorough understanding of what it is you've been presented with. And for that reason, it's really important that there is a cross-sectional community and a really broad pool of candidates from which they can draw their data."

(Asian - Indian, Man, 41-45 years)

> "...to sort of see how trends for certain ethnicities and if they're prone to certain diseases, maybe."

(Asian - Bangladeshi, Woman, 41-45 years)

> "… the heart foundation, etc, they need to be keeping a track of data as well to understand what the vulnerable groups are, which groups are most affected, which community is most affected, and that allows us to plan."

(Asian - Indian, Man, 41-45 years - exploration lab)

> "Yeah, the way the pandemic has affected BAME communities has obviously been disproportionate. And we would only know that if we can analyse data and see how many cases have come about from communities, ethnic minorities, in comparison to obviously other communities. Yeah, I think there is a massive goal to help tackle, sort of, if there was another pandemic, we would be able to, sort of, target resources. Helping ethnic minorities a lot more like by providing the support that they didn't get in the first pandemic."

(Asian - Pakistani, Woman, 21-24)

Others commented that they did not feel providing their data would lead to better outcomes for people of colour.

"It took me seven years to get a diagnosis and then after getting a diagnosis, it's still a hassle getting proper treatment. So, it's not that they've not had my data, not had my medical history, that they've had it for a very long time. I always give my data, but I really don't feel like anything is changing."

(Black African, Woman, 25-30 years)

"They have a lot of data on us already. But still things haven't really changed. It's about the people whose hands the data are in."

(Asian Woman, 25-30 years)

"I would say sometimes I'm a bit hesitant to share because I know we collect all these things, data and whatnot, but sometimes, I mean, it just goes into the air and nothing really gets done about it or something starts but never finishes or you don't see the fruition of like what you're giving a data to. So, yeah, I'm always a bit hesitant because you just never know that."

(Black African, Woman, 21-25 years).

"There is a lot of data and information already available about the poor health outcomes for Black and South Asian communities, ethnic minorities, and yet nothing seems to have changed/ improved."

(Asian - Indian, Woman, 25-30 years)

These accounts highlight that while most have no problem in providing their data and believe that it could improve the services on offer to Black and South Asian communities, some are still sceptical that it will result in benefits to their communities due to the lack of action and progress apparent in recent years. This challenges the narrative that people from Black and South Asian communities are reluctant to share their data but shows rather that they feel let down due to their experiences and observations.

4. Black and South Asian communities have had negative experiences of the healthcare system and fear that sharing their data will lead to racial discrimination and poorer health outcomes.

Unfortunately, participants from both the exploration labs and the community research spoke of experiences where they felt that the race and ethnicity data they shared had been used to racially profile and discriminate against them. They are now hesitant to provide this data as they fear it will result in them receiving poorer care and services.

"Although I'm likely to provide my personal details on medical forms, I do feel a bit uncomfortable providing my ethnicity because I feel sometimes it can affect the quality of services and treatments offered to me…It's a one size fits all approach when it comes to health services provided to people from the Black community."

(Black African, Woman, 21-25 years)

"My ethnicity, I don't feel right sharing that information so I tend to choose 'prefer not to say' because I feel ethnicity will influence the kind of treatment I am offered, and I can guarantee you it won't be the best treatment."

(Black African, Man, 36-40 years)

"They do take it into consideration (your ethnicity), but sometimes not in a positive way, especially for conditions like in regard to pain, like you've got neck pains or joint pains or something. They won't often give you paracetamol because there's a stigma that Black people have higher pain tolerance, like I've seen it happen first hand in the hospital."

(Black African, Woman, 18-20 years)

"Sometimes I am reluctant about disclosing my ethnicity and gender for obvious reasons like being seen as a Black woman, so I'm supposed to be 'strong' even when I am unwell and clearly weak."

(Black Caribbean, Woman, 26-30 years)

"I'm proper uncomfortable about sharing my ethnicity because I feel like once they see that I'm Black African, they won't take me seriously and will probably use generic 'statistics' to come up with a diagnosis that isn't even correct. It makes me feel really uncomfortable."

(Black African, Man, 21-25 years - community research)

Participants suggested that there was a lack of cultural knowledge and sensitivity from health professionals when treating people from Black and South Asian communities, and this leads to racial bias.

"With one of my housemates, I had to go to the ambulance with her and they said, oh, if she turns blue. And I was like, well, she's Black, she's not going to turn blue. So, like, those kinds of things are things that aren't considered as well, and I think should be. I don't know how; it's probably going to take years and like loads of updated research because it's based on a lot of historical things. But yeah, those kinds of like diagnosis and things like that should also be considered as well."

(Black Caribbean, Woman, 25-30 years)

"(The way) a lot of diseases are taught, it's usually just like you see a disease being presented on a White body or a fair body. So even with like a White skin condition, maybe, in my opinion, someone who is a darker-skinned person has fair skin. But even just the way like the curriculum itself is not really taught in a diverse way. So that therefore the doctors who are treating communities who are diverse are missing something just because they haven't been taught about people who are not White that much."

(Black African, Woman, 21-24 years)

"I think there's a lot of assuming going on, especially in that 30-minute GP appointment. With my wife, when you're talking about how when she was suffering from hair loss, they said it must be because you wear a scarf. I've had similar issues in the GP surgery. I'll go in with a certain issue and they'll be like, oh, it's linked to this random cultural thing that I think you do, even if I don't do it."

(Black African, Woman, 21-24 years)

The above accounts reaffirm some of the findings from our other research into the experiences of Black and South Asian communities within the UK healthcare system. We have consistently found, particularly with people from the Black community, that participants of all ages, genders and backgrounds were subject to microaggressions, racial profiling and poor experiences in the healthcare system. For example, in our research for the Joint Committee on Human Rights, we found that the majority of Black people (over 60%) in the UK did not believe their health was equally protected by the NHS compared to White people. When combined with the key findings from this report, it is especially worrying that an institution that is supposed to help people appears to be the very institution that is inflicting harm.[15]

5. Black and South Asian communities want to be informed about how their data is/will be influencing research, design, and planning of healthcare services.

Many of our participants from the exploration labs and community research said that they could not recollect having a conversation with anyone about their patient data and how it was being used. Others stated that they felt there was a lack of communication and follow-up on a local and national level about the outcome of data collection exercises.

The lack of communication regarding how data that is collected has been used may explain why participants from the community research felt they were being forced to share their data to receive the care they needed. Requesting such sensitive data without providing useful updates can leave patients feeling coerced and suspicious of data-sharing activities (see Finding 2).

“If I had my way, I wouldn’t give my personal details out especially if I don’t know what it is going to be used for, but I do fill it in because at the end of the day if you don’t fill in these details you won’t really be seen or respected”

(Black African Caribbean, Woman, 51-55 years)

“I don’t really like giving my personal details. I feel like some questions are irrelevant and sometimes quite intrusive.”

(Black African, Woman, 26-30 years)

“NHS requires details that have no connection with medical. My religion, ethnicity has nothing to do with my illness. What are they going to do with this information? All I need is treatment.”

(Black African, Man, 16-20 years)

“It’s not like I have a choice anyway. I do feel like sometimes people are indirectly forced to provide their personal data though.”

(Black Caribbean, Woman, 26-30 years)

“I feel it has become the norm. I feel like I am forced to provide my personal details as I am not given a choice whether or not to fill it in. I am just told to fill in the form with my personal details.”

(Black African, Woman, 26-30 years)

However, participants recognised that their data could be used to improve services and health outcomes for them and their communities, and if they were made aware that this was happening then more people would be motivated to provide their data. This could then lead to more accurate and improved data collection.

> **"It will be good to find out what happened to the data or what action will be taken so we can volunteer and give the information. But what will happen too afterwards?"**

(Asian - Bangladeshi, Man, 36-40 years)

> **"I think over the years you're always doing research, then you never hear of the outcome of what they found or what can be done afterwards. And I think it's always good to know."**

(Asian - Bangladeshi, Woman, 41-45 years)

> **"If I've given you some information and then I've heard back from them and I think, OK, that's interesting, I might encourage my family, my friends, to give help with the research too, so we can get more out of it. But I just think we never hear back from them."**

(Asian - Bangladeshi, Woman, 31-35 years)

> **"Being able to see the outcomes of the use of our data would be good and some tangible benefits to our communities."**

(Black African, Man, 21-24 years)

A small number of participants were able to recall a time when they were asked and did provide their details for a specific research purpose, and they described the positive feeling of being followed up with and seeing action being taken.

> **"I was asked at my local GP if I wanted to provide my data for a new clinic focused on heart disease, cholesterol and high blood pressure. I did give my information and health background, and later they got back to me to say that the clinic would be starting and whether I would be interested in coming along, which was good."**

(Black Caribbean, Man, 41-45 years)

It is important to recognise that these communities are willing to share their data, but the healthcare system must start viewing them as key stakeholders in healthcare and not an afterthought. Every account from a member of the Black and South Asian community of a positive experience sharing demographic data must serve as evidence of what is possible when transparency and cultural considerations are embedded into the data-sharing processes.

6. Black and South Asian communities report that local services do not reflect local needs.

As part of the exploration labs, we asked participants whether they felt as though their local services took their race, ethnicity, religion, and culture into account. This is especially important given that data-sharing should enable local services to be suitably tailored to serve local demographics, which links to Findings 3 and 4.

Most of the people who explicitly responded to this question said “no”, that their local services did not take any of these factors into account. A small number of those who responded were unsure, and an even smaller group of people answered ‘yes’, that they felt their local services took all of these factors into account. As we engaged participants further on this question, it was clear that many were unsure, perhaps had not thought about this previously and were spending time reflecting. As the conversations continued, they began to respond more by referring to individual characteristics about themselves and how they felt these were not taken into account.

The accounts shared below further illustrate the importance of the connection between the data being collected and the development of culturally nuanced treatments and services.

> **“At the local level, certain things have been missed like my ethnicity, being Afro Caribbean.”**

(Black Caribbean, Man, 41-45 years)

> **“I know my uncle had a very specific disease that was around eating too much cassava, and that’s just something that you wouldn’t be trained to look out for. I know there are some issues with, like sickle cell. There’s a young boy who had medical complications of sickle cell anaemia and he wasn’t treated properly, and they didn’t know how to handle his care properly. So, I just think, Yeah, it starts with the research and understanding, education and knowledge.”**

(Black African, Woman, 18-20 years)

> **“I go back to, you know, the responsibility of those at the front end of this process, that they do need to be a bit more forthcoming in terms of trying to understand the candidates and who they are, and what their individual needs are so that we can plan for that, and that will provide greater access to services and better optics, but the data is only as good as the person asking the questions.”**

(Asian Man, 41-45 years)

The participant quotes above are from participants of different genders, ethnicities, and geographical regions in the UK. Yet they all highlight the similar challenges faced: a lack of local services that take into account how religion, ethnicity and race influence health beliefs and practices (including diet and views on medical examinations). This in turn shapes their willingness to come forward for treatment and support.

Furthermore, participants expressed how a lack of accessible information resources, especially translated content, showed how little local services adapt to meet their communities' needs. If local services cannot even meet the communication needs of their local community, they feel there is not much chance of greater adaptations, such as more culturally informed services.

> **"I also think what was said about the older generation, I think it comes down to understanding as well. Maybe they don't understand. And also, especially my parents, they migrated to the country, although they've been here for a while, for many, many years, over 50 years. So, it's a bit different for them. But let's say people who haven't been here for X amount of time, they may not even understand the form or the format of it. They don't have an understanding and therefore they're not going to sign something they do not understand. So that's something I would say, maybe the language barrier."**

(Asian - Bangladeshi, Woman, 41-45 years)

> **"For example, my parents, my mom isn't able to speak English and she never has. She can do the basics, but she's not fluent in English. And so when she goes to the doctors, she prefers it to be an Asian doctor where she can communicate with them in their language, than an English doctor who would struggle understanding my mom's English and she can't communicate with them and no there's not always the opportunity for people that aren't able to speak English to have access to doctors that speak their language or a language that they both speak and even information like leaflets and things. I think it can be more accessible in other languages and not just English."**

(Asian - Pakistani, Man, 31-35 years)

This suggests that more needs to be done to ensure that health services have the appropriate medical resources and content to communicate effectively with people from all backgrounds. Patients from Black and South Asian communities must be empowered to express their medical needs and fully understand the information, advice and instructions being shared by healthcare professionals. Otherwise, there is a risk that members of Black and South Asian communities, especially those newly migrated or who have English as an additional language, will be deterred from engaging with the healthcare system, leaving their medical needs unmet.

7. 'Tick box' options are inadequate for collecting data on race and ethnicity.

The lack of culturally nuanced local services could be due to a lack of accurate data captured on people's race, ethnicity, religion and culture. This lack of data is usually blamed on the reluctance of people, especially in some of these ethnic minority communities, to share this data. However, this research, from both the exploration labs and community research, suggests that this is not the case.

However, although most participants shared that they provided their data when asked for it, some mentioned that they often found providing data on their ethnicity challenging. Several participants flagged that the options, as they are often presented on a form, do not include a category that they feel describes them. They described how they might select 'other' or 'prefer not to say' or sometimes select one of the categories that they connect with, even if it is not the whole picture. We have to consider that ethnicity is not a definitive category; people often have multiple different ethnic origins that they identify with rather than just one. If we want to understand people's experiences based on the colour of their skin, then we should probably ask them to tell us the colour of their skin. However, if we are truly interested in the genetic, cultural, and experiential impact of ethnicity, then we need to start collecting data that more accurately represents this.

"Quite a lot of the times on these forums, especially under the Black bracket, you are either Black Caribbean or Black African. I have parents from both backgrounds, and that's never really an option. So also, like, just to kind of tie into the previous question, I think it kind of shows the ignorance in this idea of how we see race, you know, what happens if you don't fit into this box? And obviously it's not a big issue. I usually just tick the Caribbean box because I've grown up in the Caribbean side of the family. But I just think it just kind of shows, you know, not everyone can be included in these things."

(Mixed - Black Caribbean and African, Woman, 25-30 years)

"I'm like the fourth generation here. And when I read it and it says your ethnic origin and then says, like what country I'm from, I say I'm from Bangladesh where my parents, my grandparents were and it's quite strange because I don't see myself as a Bangladeshi. I actually see myself as a British Bangladeshi because, you know, I was born here, and my parents hold their lives here. So, you know, it's quite strange when they don't have the option of putting the British Bangladeshi on there."

(British Asian - Bangladeshi, Woman, 41-45 years)

"I always prefer not to say. I always put Black other and that just makes me feel silly. What is that, is there a Black other anyway? Yeah, so that's kind of one of the reasons I don't do it, because I'm like, well, I don't see myself represented here. So, if I'm just going through like a random form and it's not explicitly said you have to fill this out and I can but prefer not to say, I would prefer to put that."

(Black Woman, 25-30 years)

We would also like to note the shortcomings of our (ClearView) data collection method which limited the extent to which participants could specify their race and ethnicity. Although we did offer participants the free text option, in practice we could have done more to ensure participants were able to classify their ethnicity appropriately. This is captured in the quotes below:

"I think having more free text or having availability to have a longer list or something, I don't know, like the way you can choose a country that has all the countries in the world. I know it's hard to have all ethnicities in the world, but especially my community is not a very small community where we are quite representative and especially in London, but I've just never seen it. So, I also put in Asian other and then write in the free textbox where I am. And I know in research I will be classified as Asian other which is, what does that mean, like you're not really getting me as a person with that data?"

(Any other Asian background Woman, 25-30 years)

> **“One of the systems that we use, there is an option, for example, Caribbean, Asian, Sri Lankan, Somalian and so on. So, it can be a lot more specific, but staff usually don’t care. And if, for example, patients are presented with the booklets and things similar to the centres, and limited options, then they wouldn’t know that. You can make it more specific. So, I think the categories are not perfect and you have to take some good data, but it can go a bit further.”**
>
> *(Black African, Woman, 25-30 years)*

These responses highlight the importance of recognising the links between identity, ethnicity and nationality but also the need to take some time to reflect on how effective current systems are in capturing accurate demographic data. For many, it was clear that it is not just a case of ticking a box but also of how they feel represented and understood as part of a minority group. Researchers and academics often refer to the lack of representation in the data, but has as much attention been paid to how those who are developing and designing research studies are asking questions on ethnicity, race, and national identity? Limited research is available in this space; however, multiple study authors often talk of ethnicity data gaps.[16, 17, 18, 19]

Scobey, Spencer and Riley (2021) found in their research on race and data quality, “Accurate ethnicity coding to the most granular code possible is crucial, because of significant differences between ethnic groups in terms of health outcomes, experiences of health services, health risk factors and wider determinants of health such as deprivation. The proportion of records coded as ‘other Asian’, ‘other Black’ and ‘other White’ is higher in health records than in other sources, indicating miscoding. This is unsatisfactory given differences in health risks within broad groups, for example between Pakistani, Bangladeshi and Indian groups, and between Black Caribbean and Black African groups.”[20]

The NHS race and health observatory also recently published research identifying five principles to follow when writing and talking about race and ethnicity (Appendix 1).[21] As helpful as these resources are, as we can see from the accounts of participants, using the ‘Black other’ category or not completing questions on their race and ethnicity may be linked to the lack of categories provided that make people feel represented and understood. Further research into what these would look like and further consultation with people from a range of Black and South Asian backgrounds is vital in the development of methods for collecting accurate and sensitive data on identity.

Overall Project Reflections and Conclusions

The research shows that there is a gap in the understanding of how patient data is used for people from Black and South Asian communities across the UK. Most of the participants we spoke with during this research had a clear understanding of what patient data is and how or where it is collected.

However, when it came to the different ways their patient data is used, many of the participants felt confident that they were fully informed about where their data is shared and used but were then surprised when they saw that it could be used for purposes well beyond their individual care, or even their local services. This shows that, even for those who feel confident about what patient health data is, there may be gaps in their understanding.

Why is there a gap in understanding of how patient data is used?

We explored this gap in understanding further and discovered it is driven by several factors, including:

1. Not being fully informed about the way their data is used when it is being collected
2. Having experiences and hearing stories about the system and the people who work within it that cause distrust
3. Not seeing the results, or impact of, the research that uses their data

Nearly all of the participants we spoke to, from both Black and South Asian communities, from different age groups, genders, and geographical locations, reported that no one in the healthcare system had ever had a conversation with them about their data and how it is used. Some of the participants also mentioned that they do not remember seeing this information on forms that they have completed, and when they provide their information, they do so with the understanding that it will be used for their health care and nothing else. This gap in communication about how their data is being used leaves people uninformed and unaware of what is happening to their data. Furthermore, participants had doubts about the need to disclose their ethnicity or religion for medical care and therefore said they often did not want to provide it.

How does trust in the NHS impact understanding of how patient data is used?

Many of the participants also spoke about being nervous when it comes to sharing their personal data with the NHS. The reasons behind this limited trust include:

1. People's confidence in the competency or willingness of the NHS to protect their data is limited.
2. Little visibility of improvements to health outcomes for people from Black and South Asian communities means little social trust in the system.
3. Negative experiences, or hearing stories about others' negative experiences, such as racial profiling, bias, or outright discrimination damages trust.
4. No feedback about how their data is leading to positive change and improvements in services and treatments for people in their communities means people doubt if this is the reality.

Some of the participants expressed fears that the NHS would willingly share their data with third-party organisations that they would prefer not to share their data with (such as insurance companies) and that the NHS would not be able to protect their data from being accessed by unapproved people or companies, for example, due to data breaches.

We also heard stories about how the limited knowledge of healthcare professionals has led patients to believe they are not seen as important or a priority. These participants described situations where a lack of appropriate medical and cultural knowledge meant they did not receive a suitable diagnosis, treatment, or care. This lack of knowledge and understanding from healthcare workers is reflected in other research studies, including research work that ClearView has conducted and the National Cancer Patient Experience Survey, where respondents who were Black reported having to visit the GP more often than their White counterparts to get a referral for a cancer diagnosis.[22, 23] Numerous examples were given by people from Black and South Asian communities who either had difficulty getting a diagnosis because their symptoms appear differently due to the colour of their skin, or whose healthcare professionals did not know how to treat their condition because they did not have the relevant medical knowledge (such as in many sickle cell cases).

When we explored this distrust further, we discovered that many of the participants had also either had negative experiences with the NHS themselves or had heard negative stories from close friends and family. This left these patients feeling nervous about providing their ethnicity or other demographic data in the future for fear of being discriminated against. Many of these participants described how their local services do not properly take their race, ethnicity, culture, or religion into account when delivering treatment and care, resulting in poor care and generating further distrust in the system. The history of discrimination experienced by people in Black and South Asian communities in the UK is compounded by these negative experiences and results in a growing distrust that can be seen at a local and a national level.

When it comes to their views on how data is collected and used, this distrust is amplified as the participants reported they never see positive outcomes from sharing their data. Many of the participants spoke about how they never hear about what happens with their data after they share it. They expressed that they would like to know more and would be interested to see what is discovered in research that uses their data. The few participants who had participated in specific consented health research studies and were informed of the findings afterwards reported positive views of the research and said that they would be happy to share their data similarly again. This highlights the importance and usefulness of feedback loops as a way of recognising the value of the data someone is providing. Similar feedback loops to those used in consented research studies could be used for research using routinely collected data, and this could improve patients' understanding and involvement in their patient data collection and use.

However, it is not enough to report the findings of research using patient data; it is also essential to take action to improve care and services based on those findings. The lack of evidence of real change and the practical benefit of sharing their information discourages participants from continuing to share it and can lead to inaccurate or limited data collection. To build trusted relationships with Black and South Asian communities, the NHS and the wider health system will need to show that they are willing to take research findings and turn them into real action to improve care and services for people in these communities.

We can no longer blame data gaps on patient reluctance to share data. The system needs to take responsibility for improving how data is both collected and used.

Despite the challenges that result in a gap in understanding of how their patient data is used, most participants reported that they willingly provide their data and believe that it can be used to improve care and services in the future. However, they also stressed that how data is collected and used and the feedback on its use need to change for this to become a reality. It has been suggested that there is a lack of data on factors such as race, ethnicity, culture, and religion, and because of this, culturally nuanced improvements to care and services do not emerge. As we can see in this research, most people from Black and South Asian communities are willing to share their data and do share it; therefore, patient reluctance to share data cannot be solely responsible for why data gaps exist.

When it comes to how data is recorded, there is one obvious challenge: Many of the forms that participants described using to provide their data, both paper and online, provide only limited options to respond to questions about their identity (including questions on race, ethnicity, culture, and religion). This means that for some participants it was difficult to respond honestly to the question as none of the options describes their identity accurately. This also leaves them feeling excluded or unseen. Forms can also be confusing to people who do not speak English or who did not grow up in the UK, as often they will not have seen these types of questions or categories previously. This highlights the interesting challenge of collecting identity-based data, as categorisations tend to be socially constructed (i.e. meaning different things to different people). This means that when collecting data on individuals' identities, the healthcare system needs to do so considerately and respectfully.

One way to avoid the limited nature of forms for providing detail about complex topics such as identity would be to provide the information verbally, through a conversation with a healthcare professional which would necessarily include reflections on knowledge, attitudes and practices that may be relevant to health. However, none of the participants could recollect having a conversation of this type, and one participant, who works within the NHS, even reported that they have witnessed colleagues taking shortcuts when recording this type of information, preferring the use of collective or overarching categories, over recording more detailed and specific data. The important point to note here is that this specific level of detail, that accurately represents an individual's identity, is necessary if we are truly interested in the genetic, cultural, and experiential impact of ethnicity. Detailed information is key, both for an individual's healthcare and to inform and improve treatment and services for minority communities. If this data is not correctly recorded, then it cannot be used to support an individual's care or be used as data in research to inform improvements to care and services for the future.

However, collecting the data is not enough. The people who are analysing the data need to understand the importance and relevance of this level of specific data that accurately represents an individual's identity. As well as this analysts must have a high level of cultural awareness and understanding of a diverse range of cultures and health beliefs and attitudes to health and health services so that they can interrogate the data appropriately. There has been an increase in understanding in recent years that grouping all minority ethnic groups under one umbrella is inappropriate because it erases their diverse experience. We need to move away from using simple overarching categories to refer to groups of people and look to understand more about the intersectionality of different identity characteristics and how these might impact health and disease.

Without an understanding of the nuances of identity, data analysts are likely to ignore important data points and miss valuable insights that could improve care and services for these communities.

If we want to improve the quality of services and care that are offered to Black and South Asian communities then it is vital to understand the identity of the individual patient, including their diet, herbal remedies they may use, their religious beliefs, and any associated impacts these may have on their health or care. Without this information there is an increased chance of mis- or under-diagnosis, providing incorrect treatment, and poorer health outcomes. At a community level, if we do not record, analyse and report detailed information, broken down into the most specific categories possible, then we lose out on learnings that can be applied to larger community groups and potentially save lives.

What are the aspirations for the future?

Most of the people who participated in the research study were, despite the challenging experiences many have faced, optimistic about what could be done to improve how their data is used in the future. Many of the participants spoke about how improving the cultural and medical knowledge of healthcare professionals and encouraging more diversity in both healthcare and data analysis could lead to great improvements in both treatments and services for people from Black and South Asian communities across the UK. However, they also pointed out that to achieve real change, trust between these communities and the system and the individuals within the system will need to be improved. They were mostly hopeful that this trust could be achieved, but this will require a commitment to anti-racist and anti-prejudiced practice, and a feedback loop that communicates back to communities the research findings and the actions being taken to create positive change.

ClearView Recommendations for Policy and Practice

Based on our findings from both the exploration labs and community research and our experience and knowledge in this area, we have provided some recommendations for UPD, healthcare professionals and the wider health sector to move forward.

1. Healthcare professionals need the resources and training to be equipped to have conversations with Black and South Asian people about what patient health data is and how it is used.

The varying levels of understanding of how patient data is used and its links to service design observed in our research suggest there is a lack of standardisation around how health professionals approach these conversations and whether they have them at all. Coupled with reports from some NHS employees who participated in our exploration labs that suggest NHS staff do not always correctly record demographic details such as ethnicity, this shows that healthcare staff may not feel comfortable talking about topics such as ethnicity and may even not understand the importance of patient data themselves.

Healthcare professionals should feel empowered to communicate information around patient data and understand the importance of having patient data conversations with patients from Black and South Asian backgrounds.

Training and resources will give healthcare professionals the necessary communication and interpersonal skills to explain, reassure and respond to queries from Black and South Asian patients. It will also encourage them to make these conversations a priority during appointments or treatment.

Training and resources should equip healthcare professionals with the skill and cultural literacy to communicate information to patients from this demographic effectively for them to make informed decisions about their data.

2. Research is needed to find a new, more inclusive method to collect identity information, including race and ethnicity so that patients can more easily and accurately provide this information.

There is evident dissatisfaction with the options available to Black and South Asian communities when indicating their race and ethnicity on forms while accessing health care and treatment. Participants mentioned that this is worsened by limiting and overgeneralised drop down and ‘tick box’ options that only allow one selection to be made.

The health sector should look both within and outside itself to identify best practices for categorising different combinations of race and ethnicity. Understanding different approaches, challenges and solutions will bring the health sector a step closer to finding methods that meet the needs of Black and South Asian communities.

If Black and South Asian communities are to provide accurate and meaningful information to shape local services, then the sector must adopt more equitable and empowering categorisations that capture their varied identities. This should always be accompanied by free text options to allow patients from Black and South Asian backgrounds space for self-identification, should other available options not suffice.

We do not underestimate the complexities that may arise in the process but recognise that unless this challenge is addressed, issues with incomplete, inaccurate or missing data collection will persist. This in turn leads to health services holding unrepresentative patient data and so being unable to provide appropriate services that meet the needs of the communities they serve.

3. People from Black and South Asian communities should be involved in decisions about what research and improvement, involving their data, is being prioritised.

This recommendation addresses the issues raised during this research project of a lack of trust in data-sharing, doubts around how data is used, and whether it benefits Black and South Asian communities. Participants do not feel that they see any action being taken to improve care and services based on key areas that are important to their communities.

Like recommendation 1, beyond explaining the intentions of data-gathering, the health sector should update Black and South Asian communities on how the data they have gathered has been used to improve services. This requires a timely and transparent feedback loop so people from Black and South Asian communities can witness the benefits to their communities. Not only does consistent communication build trust but it allows Black and South Asian communities to hold health services to account.

However, it is just as important that these communities are involved in and consulted on how specific research questions are prioritised. Participants expressed that they would like to know more and would be interested to see what is discovered in research that uses their data.

Gaining a better understanding of the views of these communities on the current priorities and objectives of research using their data and working with these communities to develop an informed list of priorities is a key area of research that should be considered for the future.

The appetite to engage in data collection and be involved in shaping research should suggest to the NHS that improving data quality and representation and healthcare outcomes for Black and South Asian communities can be achieved using effective community engagement and partnership models. By involving people from Black and South Asian communities in decisions that impact data quality, representation, and health outcomes, they can begin to influence directly how their communities are impacted.

4. Health data should be used to ensure better and more appropriate representation in datasets and for research into conditions that disproportionately affect people from Black and South Asian backgrounds to improve health outcomes.

When healthcare providers are serving their local communities, especially those with a high population of people from Black and/or South Asian backgrounds, they need to ensure they are delivering services that reflect conditions that are prevalent within those communities, such as sickle cell and thalassaemia.

So, it is vital to produce enough research about conditions that disproportionately affect these communities and disseminate it amongst healthcare professionals at all levels. When this information is not available there can be fatal consequences.

It is negligent when people from Black and South Asian communities are left untreated or maltreated due to gaps in medical knowledge or misleading guidance on how to treat people from these communities. Therefore, more research should be done to understand why these needs are not being met. It is essential to determine if better or more accurate collection of patient health data or better use of this data in the design and planning of local services is needed so people from Black and South Asian communities can receive high-quality and appropriate health care.

However, if research is being conducted but improvements in health outcomes are not seen in practice, then conversations around patient health data will continue to frustrate and concern Black and South Asian communities, straining their relationship with the whole healthcare system. When changes are made to services, treatments or care based on evidence using patient data, these changes and the evidence behind them should be communicated to patients. This will open the lines of communication between patients and decision-makers, helping patients to understand how their data is impacting the services available to them and their communities. Opening these lines of communication also holds the NHS accountable as it means they have to provide the evidence behind their decision making.

5. The NHS must commit to eradicating racial and ethnic discrimination, which affects the way patient data is collected and used.

The NHS must demonstrate that they understand how important discrimination is as an issue. They should do this through an explicit commitment to eradicating racial discrimination and introduce success metrics to monitor progress against this commitment.

Acknowledging the role of racial and ethnic discrimination in the collection and recording of patient health data requires that the health care system recognises the part it plays in the lack of representative data being collected, rather than assuming that patients from these communities are hesitant to provide their data. Over the past two years, society has begun having more honest conversations about systemic racism and prejudice across sectors in the UK, which includes healthcare and medicine.

Beyond public discussion, healthcare services should develop specific, ambitious goals and actions to fill gaps in patient health data that lead to poorer health outcomes for people from Black and South Asian communities. Recommendations 1, 2, 3 and 4 are all underpinned by the need for the sector to eradicate racial and ethnic discrimination from patient health data collection and use. Ambitious as these goals and objectives need to be, healthcare services must ensure that they are accompanied by realistic short-term targets so benefits can be experienced now, by current patients from these communities, rather than promises for future improvements that may never be realised.

Appendix 1

The NHS race and health observatory - five principles to follow when writing and talking about race and ethnicity:

1. Be specific rather than using collective terminology.

2. No use of acronyms or initialisations to refer to groups of human beings.

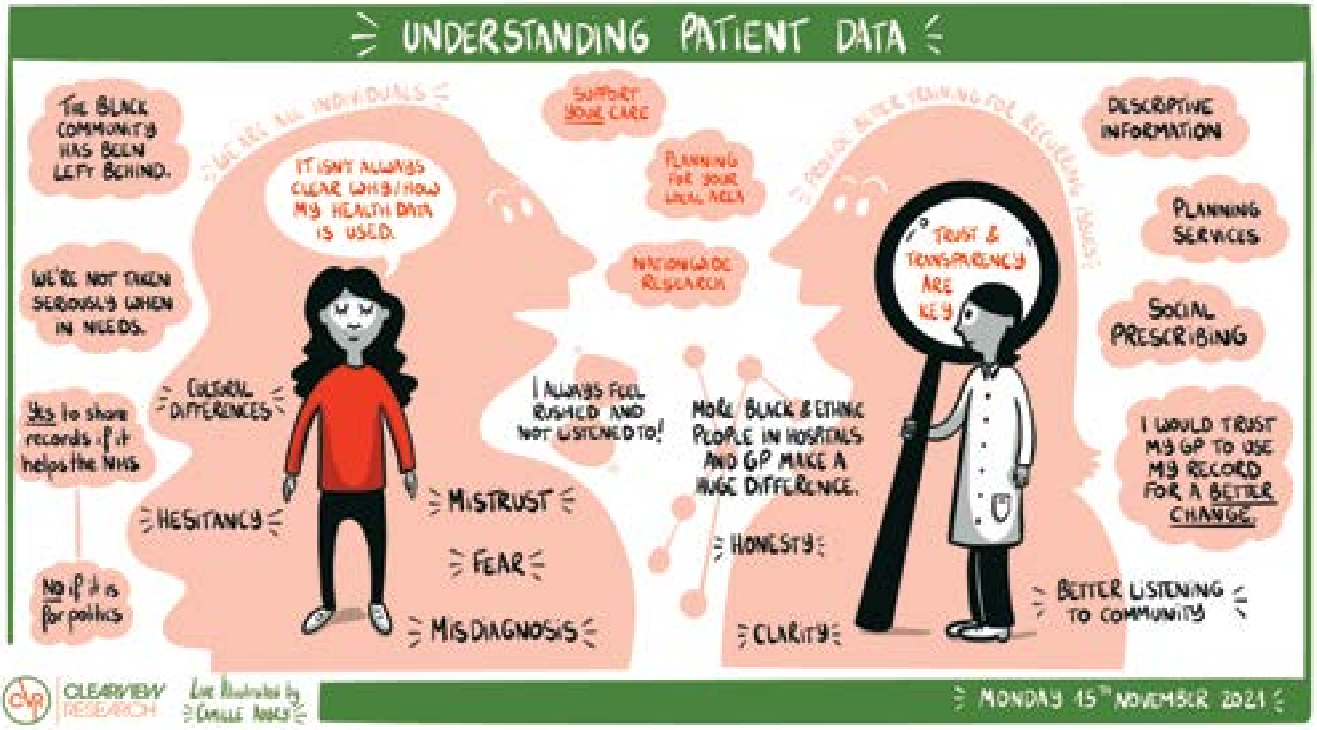
3. Context will be applied where groups are spoken about in the collective.

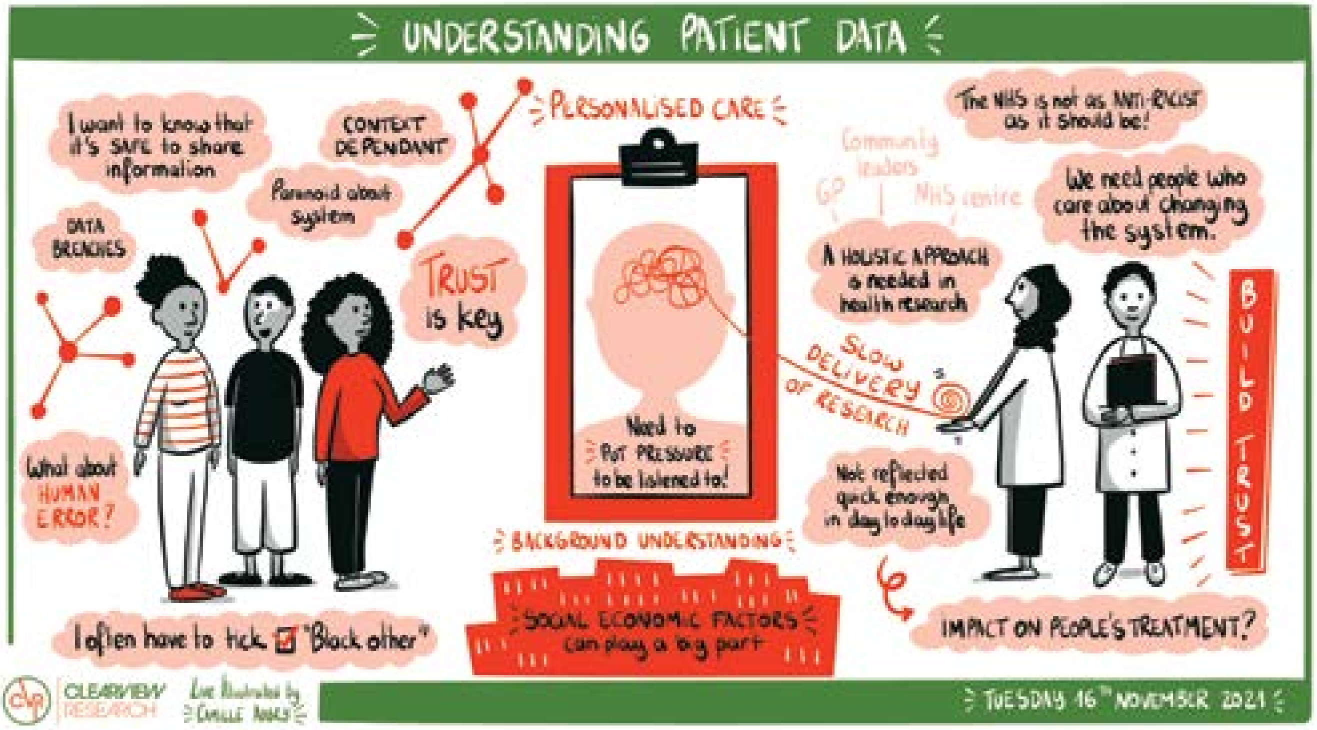
4. Transparency – the importance of being upfront about why the specific language or groupings chosen were decided upon.

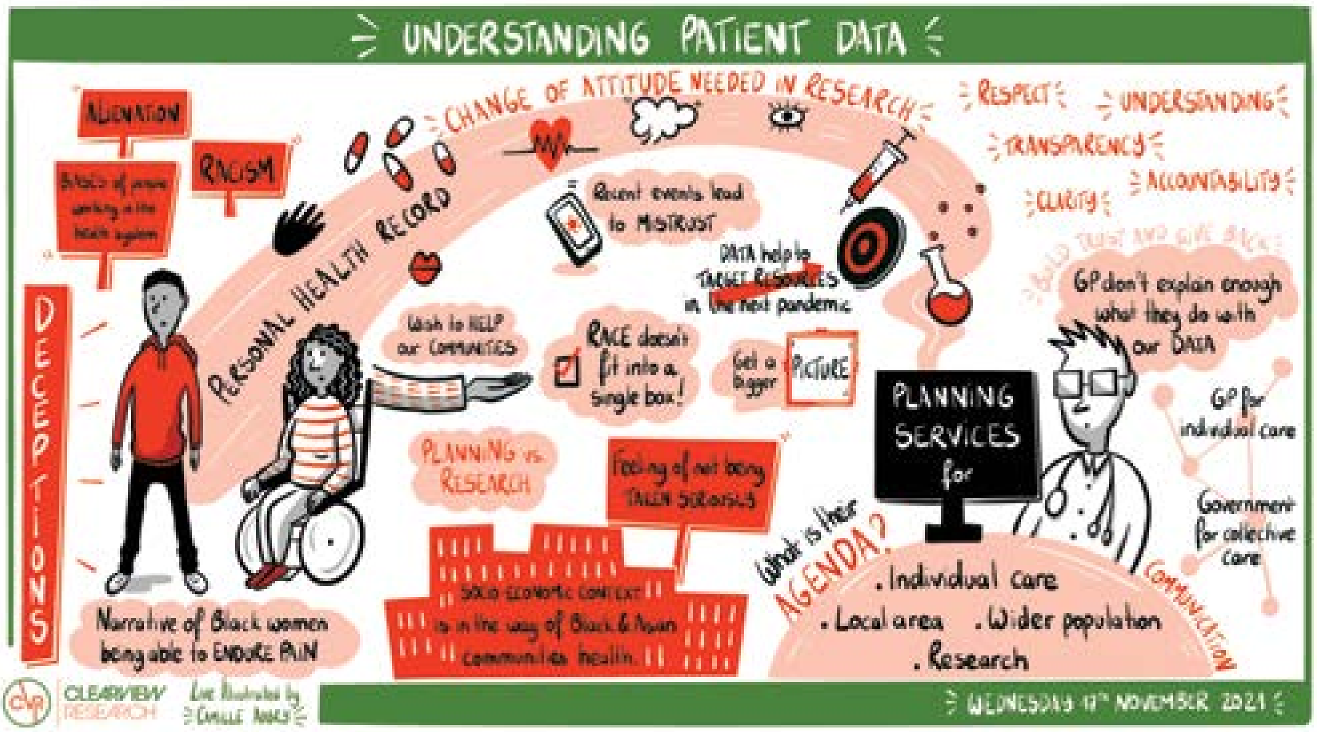
5. Adaptability – being flexible about changing approach if the current approach is deemed no longer acceptable in the future.

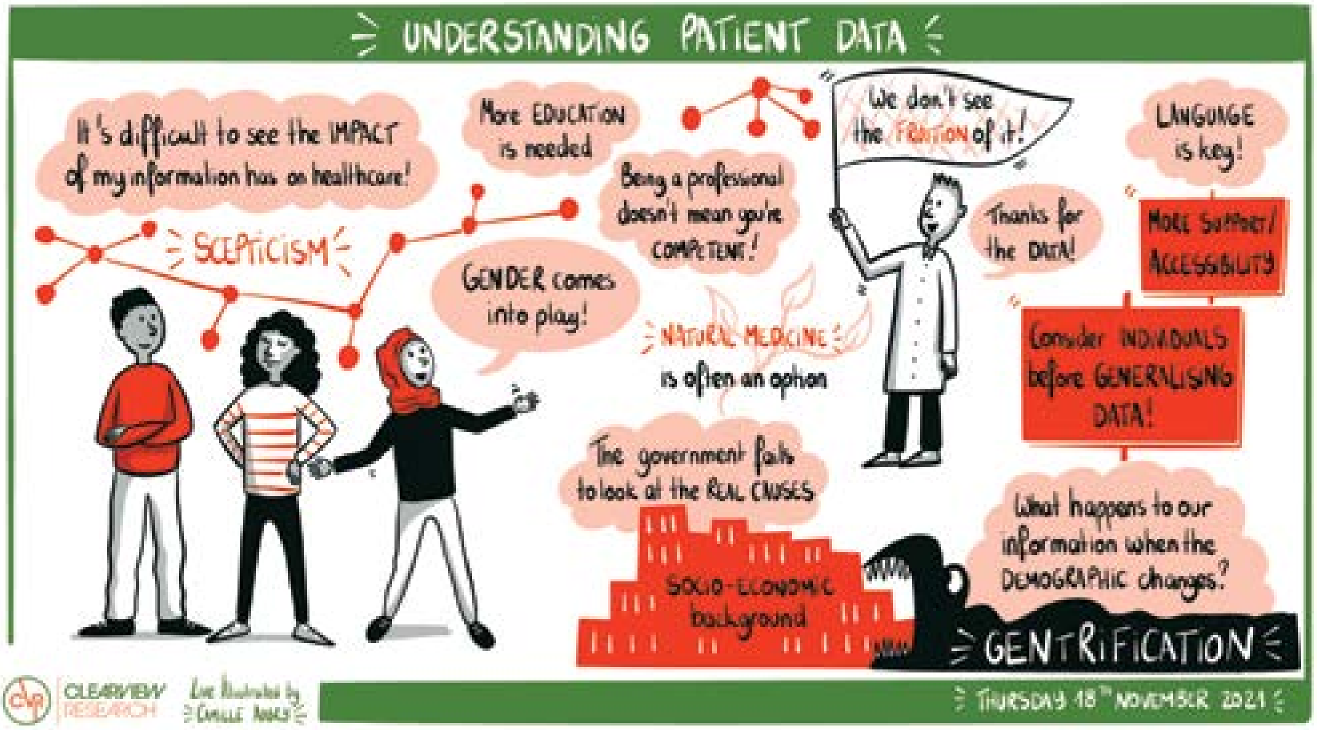
Appendix 2

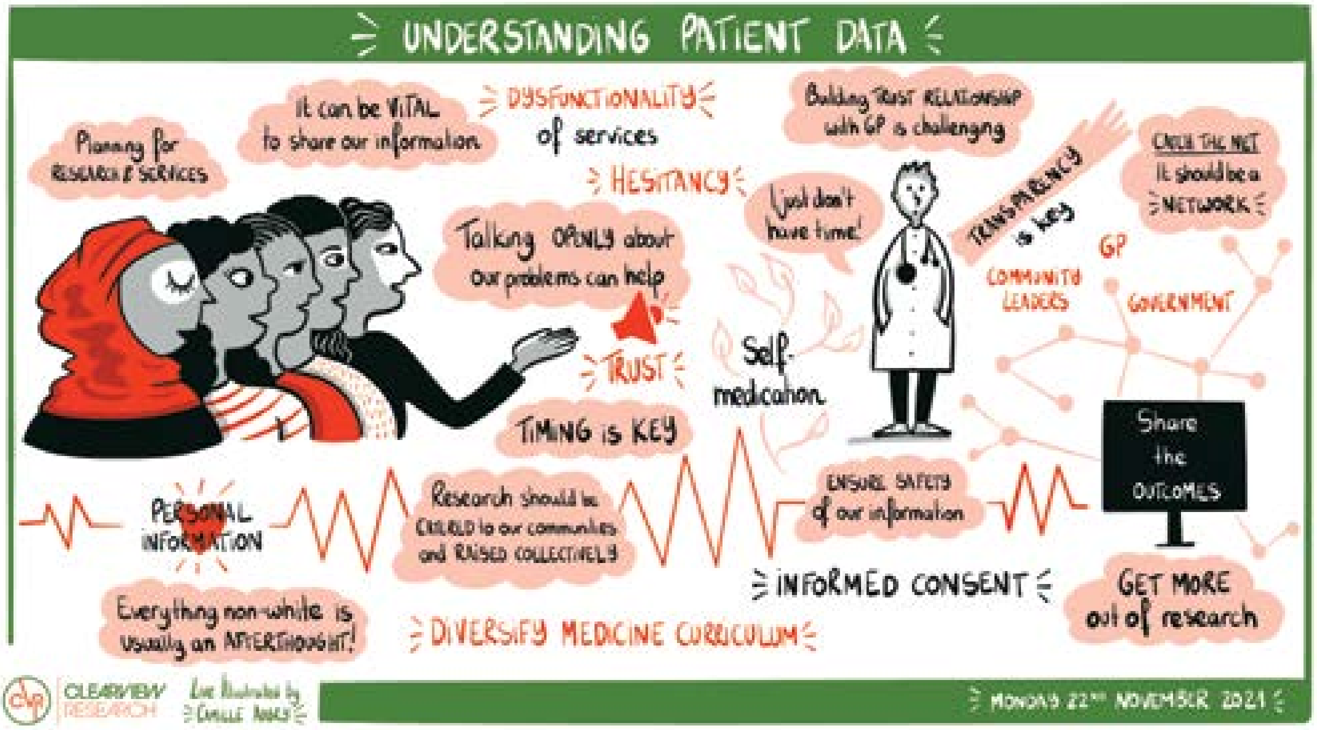
Live illustrations from Exploration Labs

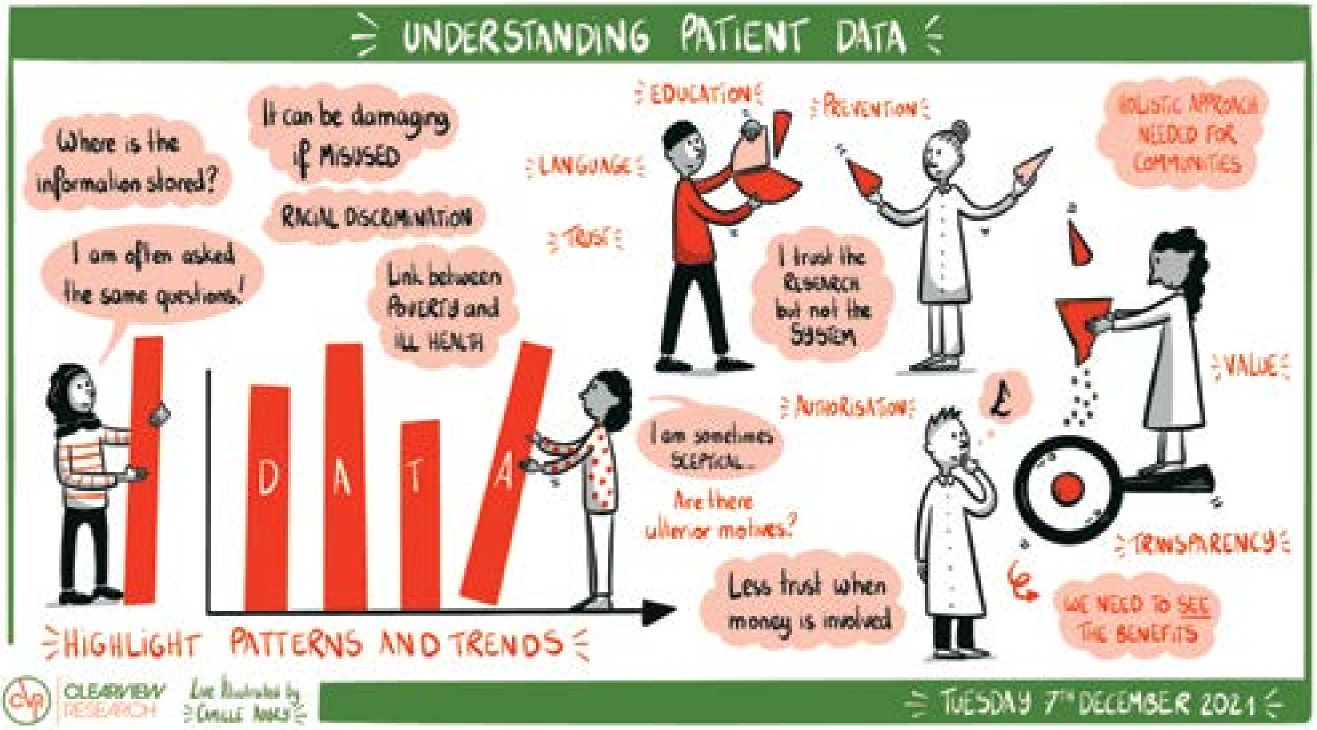

UNDERSTANDING PATIENT DATA
THE BLACK COMMUNITY HAS BEEN LEFT BEHIND.
WE ARE ALL INDIVIDUALS
IT ISN'T ALWAYS CLEAR WHY/HOW MY HEALTH DATA IS USED.
SUPPORT YOUR CARE
PLANNING FOR YOUR LOCAL AREA
NATIONWIDE RESEARCH
WE'RE NOT TAKEN SERIOUSLY WHEN IN NEEDS.
CULTURAL DIFFERENCES
Yes to share records if it helps the NHS
No if it is for politics
HESITANCY
MISTRUST
FEAR
MISDIAGNOSIS
I ALWAYS FEEL RUSHED AND NOT LISTENED TO!
PROVIDE BETTER TRAINING FOR RECURRING ISSUES
TRUST & TRANSPARENCY ARE KEY
MORE BLACK & ETHNIC PEOPLE IN HOSPITALS AND GP MAKE A HUGE DIFFERENCE.
HONESTY
CLARITY
DESCRIPTIVE INFORMATION
PLANNING SERVICES
SOCIAL PRESCRIBING
I WOULD TRUST MY GP TO USE MY RECORD FOR A BETTER CHANGE.
BETTER LISTENING TO COMMUNITY
CLEARVIEW RESEARCH
Live Illustrated by CAMILLE AUBRY
MONDAY 15TH NOVEMBER 2021

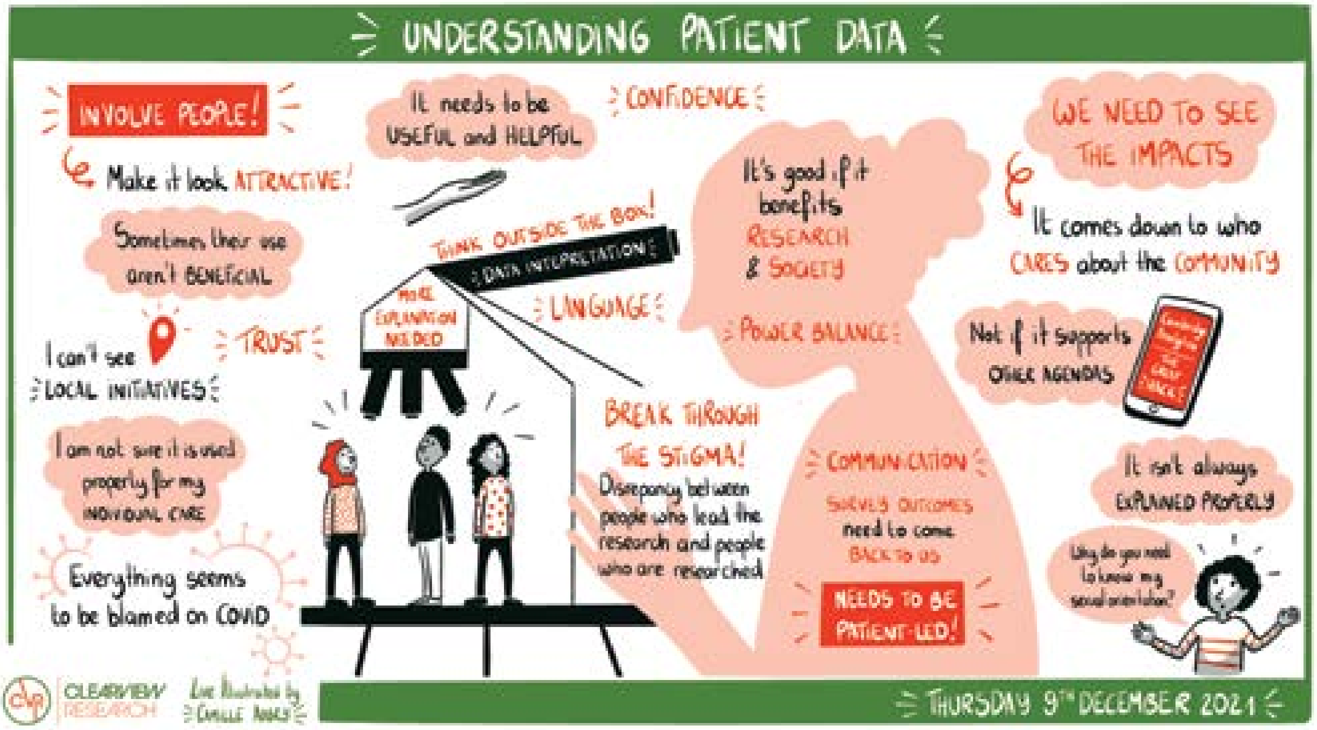

UNDERSTANDING PATIENT DATA
I want to know that it's SAFE to share information
CONTEXT DEPENDANT
Paranoid about system
DATA BREACHES
TRUST is key
What about HUMAN ERROR?
I often have to tick ☑ "Black other"
PERSONALISED CARE
Need to PUT PRESSURE to be listened to!
BACKGROUND UNDERSTANDING
SOCIAL ECONOMIC FACTORS can play a big part
The NHS is not as ANTI-RACIST as it should be!
Community leaders
GP
NHS centre
A HOLISTIC APPROACH is needed in health research
We need people who care about changing the system.
SLOW DELIVERY OF RESEARCH
Not reflected quick enough in day to day life
BUILD TRUST
IMPACT ON PEOPLE'S TREATMENT?
CLEARVIEW RESEARCH
Live Illustrated by CAMILLE AUBRY
TUESDAY 16TH NOVEMBER 2021

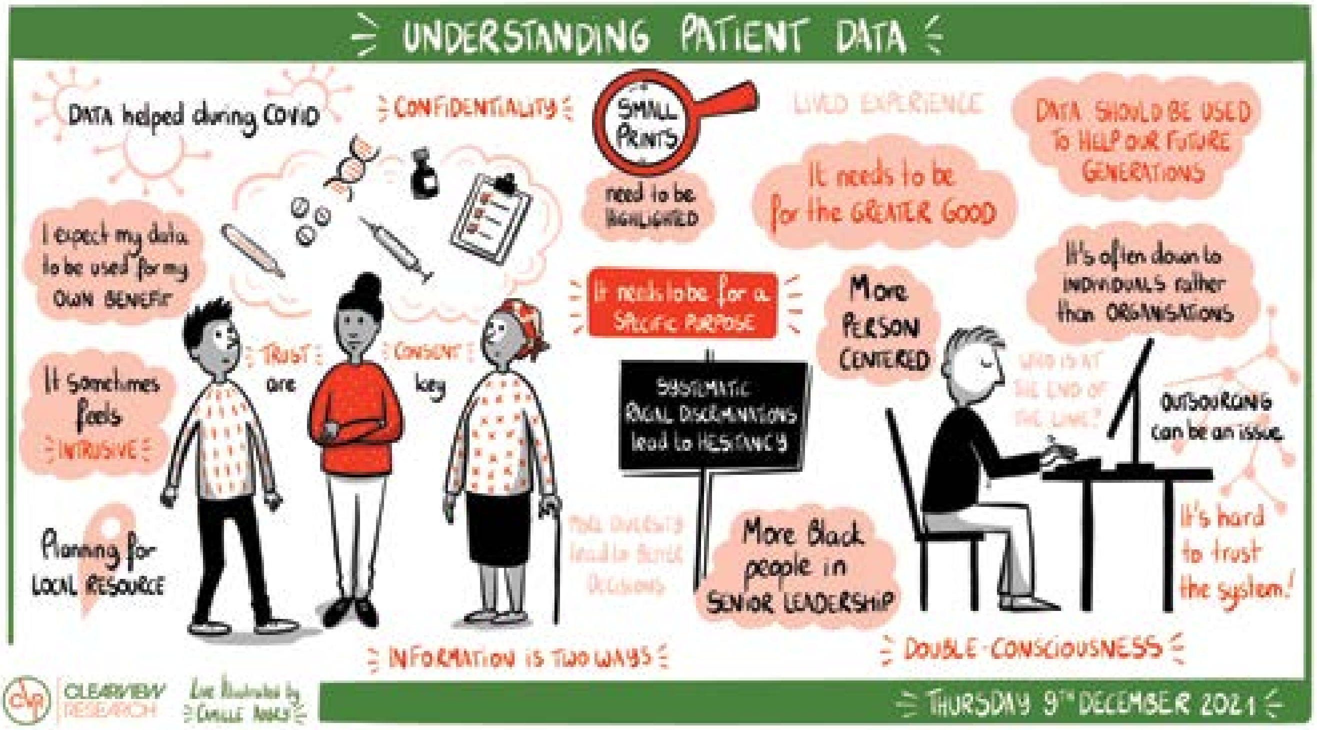

UNDERSTANDING PATIENT DATA
ALIENATION
BASICS of people working in the health system
RACISM
DECEPTIONS
PERSONAL HEALTH RECORD
CHANGE OF ATTITUDE NEEDED IN RESEARCH
Recent events lead to MISTRUST
DATA help to TARGET RESOURCES in the next pandemic
Wish to HELP our COMMUNITIES
RACE doesn't fit into a single box!
Get a bigger PICTURE
PLANNING vs. RESEARCH
Feeling of not being TAKEN SERIOUSLY
SOCIO ECONOMIC CONTEXT is in the way of Black & Asian communities health.
Narrative of Black women being able to ENDURE PAIN
RESPECT
UNDERSTANDING
TRANSPARENCY
ACCOUNTABILITY
CLARITY
BUILD TRUST AND GIVE BACK
GP don't explain enough what they do with our DATA
PLANNING SERVICES for
What is their AGENDA?
. Individual care
. Local area
. Wider population
. Research
COMMUNICATION
GP for individual care
Government for collective care
CLEARVIEW RESEARCH
Live Illustrated by CAMILLE AGIUS
WEDNESDAY 17TH NOVEMBER 2021

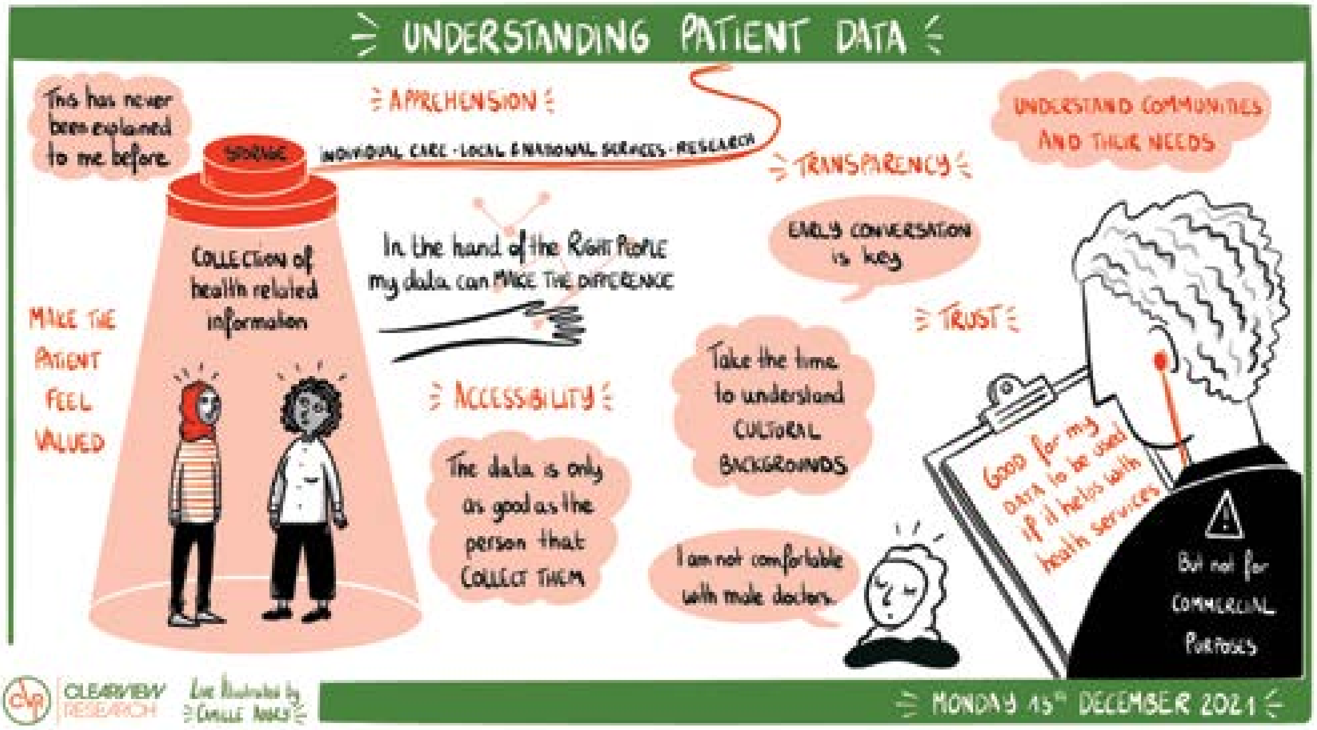

UNDERSTANDING PATIENT DATA
It's difficult to see the IMPACT of my information has on healthcare!
More EDUCATION is needed
SCEPTICISM
Being a professional doesn't mean you're COMPETENT!
GENDER comes into play!
We don't see the FRUITION of it!
Thanks for the DATA!
LANGUAGE is key!
MORE SUPPORT/ ACCESSIBILITY
Consider INDIVIDUALS before GENERALISING DATA!
NATURAL MEDICINE is often an option
The government fails to look at the REAL CAUSES
SOCIO-ECONOMIC background
What happens to our information when the DEMOGRAPHIC changes?
GENTRIFICATION
CLEARVIEW RESEARCH
Live Illustrated by CAMILLE AGIUS
THURSDAY 18TH NOVEMBER 2021


UNDERSTANDING PATIENT DATA
Planning for RESEARCH & SERVICES
It can be VITAL to share our information
DYSFUNCTIONALITY of services
HESITANCY
Building TRUST RELATIONSHIP with GP is challenging
I just don't have time!
TRANSPARENCY is key
CATCH THE NET
It should be a NETWORK
Talking OPENLY about our problems can help
TRUST
TIMING IS KEY
Self-medication
GP
COMMUNITY LEADERS
GOVERNMENT
Share the OUTCOMES
PERSONAL INFORMATION
Research should be CATERED to our communities and RAISED COLLECTIVELY
ENSURE SAFETY of our information
INFORMED CONSENT
Everything non-white is usually an AFTERTHOUGHT!
DIVERSIFY MEDICINE CURRICULUM
GET MORE out of research
CLEARVIEW RESEARCH
Live Illustrated by CAMILLE AUBRY
MONDAY 22ND NOVEMBER 2021


UNDERSTANDING PATIENT DATA
Where is the information stored?
It can be damaging if MISUSED
RACIAL DISCRIMINATION
I am often asked the same questions!
Link between POVERTY and ILL HEALTH
EDUCATION
LANGUAGE
TRUST
PREVENTION
HOLISTIC APPROACH NEEDED FOR COMMUNITIES
I trust the RESEARCH but not the SYSTEM
D
A
T
A
AUTHORISATION
£
VALUE
I am sometimes SCEPTICAL...
Are there ulterior motives?
Less trust when money is involved
TRANSPARENCY
WE NEED TO SEE THE BENEFITS
HIGHLIGHT PATTERNS AND TRENDS
CLEARVIEW RESEARCH
Live Illustrated by CAMILLE AUBRY
TUESDAY 7TH DECEMBER 2021


UNDERSTANDING PATIENT DATA
INVOLVE PEOPLE!
Make it look ATTRACTIVE!
It needs to be USEFUL and HELPFUL
CONFIDENCE
Sometimes their use aren't BENEFICIAL
THINK OUTSIDE THE BOX!
DATA INTERPRETATION
MORE EXPLANATION NEEDED
LANGUAGE
TRUST
I can't see LOCAL INITIATIVES
I am not sure it is used properly for my INDIVIDUAL CARE
Everything seems to be blamed on COVID
It's good if it benefits RESEARCH & SOCIETY
POWER BALANCE
BREAK THROUGH THE STIGMA!
Discrepancy between people who lead the research and people who are researched
COMMUNICATION
SURVEY OUTCOMES need to come BACK TO US
NEEDS TO BE PATIENT-LED!
WE NEED TO SEE THE IMPACTS
It comes down to who CARES about the COMMUNITY
Not if it supports OTHER AGENDAS
It isn't always EXPLAINED PROPERLY
Why do you need to know my sexual orientation?
CLEARVIEW RESEARCH
Live Illustrated by CAMILLE AUBRY
THURSDAY 9TH DECEMBER 2021


UNDERSTANDING PATIENT DATA
DATA helped during COVID
CONFIDENTIALITY
SMALL PRINTS need to be HIGHLIGHTED
LIVED EXPERIENCE
It needs to be for the GREATER GOOD
DATA SHOULD BE USED TO HELP OUR FUTURE GENERATIONS
I expect my data to be used for my OWN BENEFIT
It needs to be for a SPECIFIC PURPOSE
More PERSON CENTERED
It's often down to INDIVIDUALS rather than ORGANISATIONS
TRUST are CONSENT key
SYSTEMATIC RACIAL DISCRIMINATIONS lead to HESITANCY
WHO IS AT THE END OF THE LINE?
OUTSOURCING can be an issue
It sometimes feels INTRUSIVE
MORE DIVERSITY lead to BETTER DECISIONS
More Black people in SENIOR LEADERSHIP
It's hard to trust the system!
Planning for LOCAL RESOURCE
INFORMATION IS TWO WAYS
DOUBLE-CONSCIOUSNESS
CLEARVIEW RESEARCH
Live Illustrated by CAMILLE AUBRY
THURSDAY 9TH DECEMBER 2021


UNDERSTANDING PATIENT DATA
This has never been explained to me before
STORAGE
APPREHENSION
INDIVIDUAL CARE · LOCAL & NATIONAL SERVICES · RESEARCH
TRANSPARENCY
UNDERSTAND COMMUNITIES AND THEIR NEEDS
COLLECTION of health related information
In the hand of the RIGHT PEOPLE my data can MAKE THE DIFFERENCE
EARLY CONVERSATION is key
MAKE THE PATIENT FEEL VALUED
TRUST
ACCESSIBILITY
Take the time to understand CULTURAL BACKGROUNDS
Good for my DATA to be used if it helps with health services
The data is only as good as the person that COLLECT THEM
I am not comfortable with male doctors
But not for COMMERCIAL PURPOSES
CLEARVIEW RESEARCH
Live illustrated by Camille Aubry
MONDAY 13th DECEMBER 2021

Appendix A - The Discussion Guide for Exploration Labs

Introductory Questions:

1 Do you understand what we mean by patient health information / patient data?
**patient/health data definition (slide)*

2. Do you understand how health data/ patient data is:
   a. Collected
   b. Used

3. Do you understand the reasons why your health data is collected and used:
   a. For your care
   b. For other purposes
   Illustration depicting the health data collection purpose(s) and processes
   Discussion

4. Have you ever had a conversation with anyone around giving your health data for research or planning purposes (i.e., service design)?

Questions on Trust and sharing data

5. Do you trust the NHS and its related organisations with your personal health data?
   a. NHS hospital trusts
   b. Local NHS services (GP surgeries, dentists, clinics)
   c. NHS institutes (research & training, i.e., NIHR)
   d. Public Health England
   e. Research Institutes
   f. Health-Related Charities
   Discussion based on trust

6. Do you believe that providing your personal health data for research and/or service design will improve services for black and Asian communities?
   i. If yes, why? If no, why not

7. What do you feel the main challenges are for black and Asian people in your community in relation to their health?

8. Who do you feel is best placed to support your communities' health needs?
   a. GP
   b. Local NHS hospitals
   c. NHS England
   d. Local councils
   e. NHS England
   f. Government

Are you comfortable that [your preferred option] can use health data about you for your care, research and planning? Why/why not?

Black and South Asian people and patient data Conversations about: Race, Nationality and Ethnicity.

Do you know why you are asked to report on your race and ethnicity when completing forms relating to your health?

9. Do you feel comfortable responding to questions on your race, nationality and ethnicity when completing forms relating to your health? Discuss.

10. When answering questions relating to your race and ethnicity, do you feel that the categories reflect your race and cultural identity?

11. Do you feel that your ethnicity or racial identity is recorded correctly? (As you would like to have it recorded?)
    i. Does this impact your willingness to provide health data?

12. Do you feel as though your local services takes into account your:
    a. Race
    b. Ethnicity
    c. Religion
    d. Culture

Communication moving forward

13. Have you ever consented to provide your health data for research or planning purposes? Such as taking part in a research study or clinical trial; at a drop-in service, GP clinic, Health Visitor clinic?
    i. If not, would you be willing to provide your health data for research or planning purposes?

    If people say no (e.g., No because I don't trust… discussion starts based on trust, etc…

14. Do you now think that the use of health data about you in research and planning benefits black and Asian communities?

15. If not, or unsure, do you think it has the potential to benefit these communities? If so, how?

16. Would you be willing to have a conversation with a healthcare professional about providing your data for research and planning?

17. What do you feel would be a good way of approaching black and Asian communities about providing their personal health data for research and planning?

18. How do you feel routinely collected data should be used in the future? (Share infographic here as stimulus).

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